

# **Mentalizing Diabetes in the Mother-Child Dyad**

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I, Stefanella Maria Costa Cordella confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## **Abstract**

Type 1 diabetes (T1D) is a life-threatening chronic illness, the management of which is demanding for both children and their caregivers. It is widely accepted that psychological aspects play a crucial role in its course. T1D affects and is affected by psychosocial issues, both directly, through behaviour, and indirectly, through the metabolic effects of stress.

However, previous studies of T1D have not considered the role of interpersonal and attachment relationships in regulating these effects, despite the valuable understanding such research has offered in the case of other chronic, stress-related conditions.

In response, the present PhD thesis aims to develop a theoretical model for the understanding of T1D in children and their caregivers from a contemporary psychodynamic perspective, rooted in attachment and mentalizing approaches, and to empirically test the key assumptions of this model. To this end, three observational, cross-sectional studies were performed. Study 1 investigated the relationship between attachment, mentalizing, stress and diabetes outcomes and self-report measures in a sample of 77 mother-child dyads. In Study 2, initial validation of a measure for testing diabetes-specific Reflective Functioning (RF) was carried out with a sample of 91 mother-child dyads. Study 3 compared levels of maternal and child RF from observer-rated measures in two dyad groups (N=55): one with good and another with poor diabetes control.

Overall, both mother and child's mentalizing, attachment and stress appear to have an impact on diabetes outcomes, with important gender differences. However, the mechanisms that mediate the relationship between these factors require further elucidation.

Our results support the theoretical model proposed and establish an empirical framework for further research on this topic, while also highlighting the need and feasibility of developing mentalization-based interventions for diabetic children and their caregivers. At the same time, findings from these studies point to important limitations of the proposed theoretical approach, and directions for future research.

## **Impact Statement**

Type 1 Diabetes (T1D) is a common and costly chronic illness, the onset of which generally occurs in childhood. Its management implies a constant assessment of blood glucose levels (at least 4-times-per-day), a careful consideration of food intake and exercise, and regular medical visits. Diabetes care is widely affected by psychological aspects, and its proper compliance is key in order to avoid medical complications like retinopathy, cardiovascular disease, nephropathy and neuropathy. Furthermore, the impact of diabetes upon the patient's life has strong implications for their mental health.

In childhood, the child and their caregivers experience both the treatment and the impact of T1D together. Indeed, both children with T1D and their caregivers are at a higher risk of mental health difficulties. In addition, the psychological features of the caregivers influence the way in which diabetes management is performed; for example, a caregiver's stress levels affect the child's treatment adherence.

However, a comprehensive model for understanding the psychological dimension of T1D in children and their caregivers does not currently exist. The absence of such a model has resulted in poor clinical practice with this group of patients.

In response, a model for understanding T1D in children using a contemporary psychodynamic perspective rooted in attachment and mentalization theory has been developed in the present thesis. We argue that an understanding of attachment and mentalizing strategies provides a gateway to better treatment and improved outcomes. This is not only of psychological importance, as there is an intrinsic

relationship between stress regulation and the attachment system, and stress is a known risk factor in both the course of diabetes.

The results of the present PhD thesis establish an empirical framework for further research on this topic, suggesting the necessity and feasibility of developing mentalization-based interventions for diabetic children and their caregivers.

In recent years, mentalization-based interventions have demonstrated their effectiveness, supported by strong evidence. Although these interventions were initially developed for the treatment of Borderline Personality Disorder, they are currently being adapted for use with other conditions (e.g., eating disorders, depression, trauma, and drug addiction).

The current research establishes the basis for the development of a mentalization-based treatment (MBT) for children with Type 1 diabetes and their caregivers. This would allow clinicians working with children with T1D to have a clear, evidence-based framework with which to orientate their work.

More importantly, policymakers may make use of this approach, considering that MBT has been proved to be cost-effective.

A treatment for diabetic patients based on mentalization could be implemented in public hospitals, both for improving diabetes control, thus reducing medical complications, and to promote better mental health in order to prevent psychopathology. This would both substantially enhance the quality of life of diabetic patients and their families and support a reduction in costs to public health services.

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*You moved to my representational world just before I started to dwell on it as never before. Thank you for staying so close.*

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*Thank you for making me feel safe.*

## **Chapter 1**

### **Type 1 Diabetes from a Psychosocial Perspective**

#### **Introduction**

Diabetes is a chronic condition that impacts all aspects of a child's life. Its emergence – often in the context of previously normal development – forces the child to adjust, both physiologically and mentally, to a disturbing and permanent new reality: a precarious balancing act in which both the child and the disorder must adapt and coexist.

Research into the psychosocial dimension of Type 1 diabetes (T1D) has aimed to understand the role of psychosocial factors in both the onset and course of the disease, as well as the impact of T1D on psychosocial development.

However, there is a lack of integration between different approaches and findings in this area; as a result, there is no unifying theory for understanding psychosocial features in T1D. Moreover, the mechanisms underlying the relationship between psychosocial factors and diabetes remain largely elusive. These are some of the issues the current study sets out to address, by focusing on the interpersonal regulation of stress – particularly through the mother-child dyad – and its influence on health.

As an introduction to the aims of the research, this chapter presents a systematic review of the literature on T1D in children and the psychosocial factors affecting the condition.

In the first part of the chapter, the objective is to familiarize the reader with T1D. In the second part, a summary of studies addressing different aspects of the illness from a psychosocial perspective will be presented, with special consideration given to the five specific areas: the relationship between stress and T1D; psychosocial problems in children with T1D; psychosocial problems in families of children with T1D; psychosocial factors affecting adherence and metabolic control;

and psychosocial interventions for children with T1D and their families. This overview will also discuss some important limitations to our knowledge of psychosocial factors in T1D, providing the rationale for the development of a more comprehensive theoretical approach to this condition presented in Chapter 2. This, in turn, will form the basis for our own empirical studies, presented in Chapters 3 to 5.

## **Methodology of the Review**

A systematic literature search was performed using the following databases: EMBASE (1947 to May 2017), MEDLINE (1966 to May 2017), PsycINFO (1967 to May 2017), Web of Science Core Collection (1965 to 2017), EBSCOhost (1969 to May 2017), ScienceDirect (1995 to May 2017) and LILACS (1982 to May 2017).

The search terms used were (Type 1 Diabetes) AND (Psychosocial\*) AND (Child\*). These generated results for 19,777 articles, books and reviews. The exclusion criteria (by title) for filtering these results were: 1) adults or adolescents; 2) diabetes-specific education; 3) cognitive theory specific concepts in specific group of patients; 3) non-representative population; and 4) Type 2 diabetes. The inclusion criteria were: 1) psychological variables; 2) children; 3); family; and 4) psychosocial intervention.

After the inclusion and exclusion criteria were applied, 250 abstracts remained. These were assessed and categorized using a second set of inclusion criteria: a) systematic review; b) metanalysis; c) longitudinal; d) N>100; e) cited more than two times by other studies; f) novel concepts, methodology or discussion; and e) complex models of understanding. Significant references cited in these articles and books were also included. At the end of this process, 101 documents were included in the present literature review.

## **1.1 Type 1 Diabetes**

Type 1 diabetes (T1D) is a chronic illness, the onset of which generally occurs in childhood and adolescence. It is caused by the inability of the pancreas to produce the hormone insulin due to destruction of the beta cells which perform this function.

Insulin is the hormone that allows glucose to enter into cells. Without it, glucose remains in the blood, creating a homeostatic imbalance that can lead to coma or even death. A T1D sufferer therefore needs exogenous insulin in order to survive. Managing this requirement is a key component of current treatment.

### **1.1.1 Epidemiology**

T1D is the most common chronic illness in childhood. Its prevalence globally is unknown; however, in the United States the annual incidence is 24.3 cases per 100,000 people per year (Dabelea et al., 2007). Data from the 2015-2016 National Diabetes Audit for England and Wales puts the prevalence of T1D in people aged 0 to 15 years old at 195.4 per 100,000 of the general population. In the period covered by the survey, 2,834 children and young people aged 0 to 15-years-old were diagnosed with T1D, suggesting an incidence of 25.9 per 100,000 of the general population. The same audit found that the incidence of T1D was increasing year on year (Royal College of Paediatrics and Child Health, 2017).

Worldwide, this annual increase in incidence is estimated at 3% (Kharroubi and Darwish, 2015), with the biggest rise occurring in the 5 to 9-years-old age group (Hummel et al., 2012).

It is predicted that between 2005 and 2020, cases among children under 15 years of age will increase by 70% (Patterson, Dahlquist, Gyürüs, Green, and Soltész,

2009).

The precise reasons for this rise are not known but different hypotheses have been advanced. It is important to consider that T1D was uncommon and rapidly fatal before the discovery of insulin in 1922. There is little information about diabetes before that period (Gale, 2002), although it is reported that 86% of children under age 16 presenting with T1D died of ketoacidosis (Joslin, 1923). A common supposition is that something has changed in childhood diets to cause the current increase: it has been claimed, for instance, that early consumption of cow's milk could be an important environmental trigger (Harrison and Honeyman, 1999).

Other proposed causes include viral infections like enterovirus, rotavirus and congenital rubella (Graves, Norris, Pallansch, Gerling, and Rewers, 1997) and the loss of certain protective factors in the environment (Todd, 1991).

Since none of these factors has yet been identified as having a clear influence on the pathogenesis of the illness (Atkinson, Eisenbarth, and Michels, 2014), the role of the environment in T1D remains controversial (Forlenza and Rewers, 2011). Moreover, these hypotheses are currently changing in light of new understandings of how genes and the environment interact (Gale, 2002).

### **1.1.2 Aetiology**

It is known that in over 90% of cases, T1D is the result of an autoimmune process, mediated by T cells, which destroys beta cells, leading to a failure of insulin production (Bilous and Donnelly, 2010). This process has a strong genetic

component, with a concordance of 50% in monozygotic twins (Bilous and Donnelly, 2010). Some interaction with environmental factors, while not yet completely understood (as discussed above), might also be involved.

One particular hypothesis is that psychological stress plays a role in the autoimmune process described above. Stress is often implicated in susceptibility to autoimmune diseases: indeed, the field of psychoneuroimmunology (Ader, Cohen, and Felten, 1995) originated in studies of the link between stress levels and compromised immune function. In the specific case of T1D, a range of research supports the idea that psychological stress triggers the chain of events leading to the death of beta cells. A good example is the so-called “Beta Cells Stress Hypothesis” (Sepa and Ludvigsson, 2006). This argues that a range of factors cause an increase in the demand for insulin production which in turn generates stress in beta cells, leading to an autoimmune reaction (especially in individuals with a genetic predisposition). These factors include overeating and accelerated growth at puberty. Importantly, they also include psychological stress which, via the release of cortisol and catecholamine, leads to beta cell hyper functioning, increased antigen expression (triggering the formation of antibodies) and apoptosis (cell death provoked by the body itself).

This hypothesis emerged from findings of studies by Ludvigsson, Sepa and colleagues. One of their seminal studies (Sepa, Frodi, and Ludvigsson, 2005) sought to assess the mechanisms involved in the onset of diabetes-related autoimmunity. It analysed data from *All Babies in Southeast Sweden (ABIS)*, a large-scale longitudinal study involving 16,070 children from birth to 2.5 years of age. The Sepa et al. study looked at blood sample data for the first 5,986 children in the ABIS

participant group – collected 1 week after birth, at the end of the child's first year and when the child was 2.5-years-old – to identify the presence of diabetes-related autoimmune antigens. This included data from children who at 1-year-old did not show diabetes-related autoantibodies. At the same time, they analysed responses to a questionnaire completed by mothers at the 2.5-year check-up on “serious life events” they had experienced since the child's birth. These included getting divorced, being subjected to violence, experiencing a serious disease in the family, experiencing a serious accident in the family, losing a relative, becoming unemployed and having a spouse or common-law spouse become unemployed.

Their analyses controlled for other factors that might influence the association between psychological stress and the occurrence of diabetes-related autoantibodies, such as T1D in the nuclear or extended family, parental age, childhood infections, the child's body weight, gestational age, birth size, delivery mode and requirement for neonatal intensive care.

The most significant association found in this study was between the experience of divorce and the concentration of diabetes-related autoantibodies. The Odds Ratio for autoimmunity after divorce was 3.6 (95% CI 1.4-9.6). The researchers also found a positive association between autoimmunity and almost all of the life events assessed in the study, even if some of these associations were not statistically significant. None of the additional factors investigated were likely to explain the association between an experience of a serious life event and autoimmunity in the child.

The results of this study were supported by a prospective study conducted by Nygren, Carstensen, Koch, Ludvigsson and Frostell (2015), which analysed



psychological stress in families who had taken part in the original ABIS research. The study sample included 10,495 children who were not diagnosed with T1D at the start of the study, but of whom 58 would go on to develop the disease between the ages of 3 and 14. These children were assessed at 2–3, 5–6, 8, and 10–13 years of age. Parents completed a measure of severe stressful life events, and other potential confounding factors (including heredity and body mass index) were assessed.

The study found a significant association between serious life events and the likelihood of a T1D diagnosis. By estimating Hazard ratios, using Cox proportional hazard regression with time-dependent covariates, it examined the contribution of each stress variable separately to avoid effects of multicollinearity (performing a separate Cox regression analysis for each exposure variable). The Hazard Ratio (HR) was 3.0, suggesting that the risk of a child being diagnosed with diabetes before 14 years of age was three times higher if the child had experienced a stressful life event, even after adjusting for heredity, body mass index and other potential confounding factors (such as size or gestational age).

The results of these studies not only suggest that personal experience of stress may play a role in the development of autoimmune diseases – which is highly relevant to the current study – they also point to a potential relationship between stressful life events in caregivers and physiological responses in their children. Although the evidence is still quite limited, and has yet to be replicated, it is extremely meaningful to the present work and will be revisited in Chapter 2.

### **1.1.3 Clinical Presentation**

In children, the clinical presentation of T1D is generally characterized by weight loss, polyuria and polydipsia due to insulin deficiency and, in some cases, prolonged and life-threatening hyperglycaemia and diabetes ketoacidosis (DKA). Around 30% of children present with DKA at onset, generally with vomiting, abdominal pain, hyperventilation, lethargy, confusion, dehydration and the fruity breath odour of ketosis (Dabelea et al., 2014). DKA due to insulin deficiency can be life-threatening (Rewers et al., 2008) and produce severe complications. Almost 1% of DKA events are complicated by clinical cerebral edema, which typically occurs 4-12 hours after initiation of treatment for DKA but may develop at any time during treatment (Gan, Albanese-O'Neill, and Haller, 2012).

### **1.1.4 Management**

According to the National Institute for Health and Care Excellence (NICE) guidelines on T1D in children (2015), the recommended management of the illness involves insulin administration, education, dietary management, blood glucose monitoring and psychosocial support.

The guidelines state that insulin therapy must start immediately after diagnosis, through multiple daily injections. If this therapy is unsuccessful, the patient should be assessed and continuous subcutaneous insulin infusion (via CSII or

insulin pump) implemented if necessary. In order to achieve proper dietary control, the patient must learn to measure their carbohydrate intake at meal times. This involves calculating how many grams of carbohydrate they are about to consume and how many grams they are permitted to eat in relation to their insulin dosage. The latter is based on an insulin-to-carbohydrate ratio that will differ for each child and requires an understanding of how the body reacts with insulin over time (for example, an ideal ratio may be 1:12.5, meaning that for every 1g of administered insulin a person can consume 12.5g of carbohydrate).

Monitoring of blood glucose (BG) levels should be carried out at least 5 times a day using a blood sample device, so the patient can administer insulin accordingly. Some patients will require ongoing real-time glucose monitoring, which triggers an alarm when insulin injection is required.

In order to gauge the effectiveness of illness control (and therefore the risk of long-term complications) the levels of glycosylated haemoglobin (HbA1c) must be measured every 3 months. HbA1c is a blood metric that identifies average plasma glucose concentration and enables average BG levels to be monitored over a period of weeks or months. A common target level of HbA1c is 48 mmol/mol (6.5%) or below. This test is pivotal to diabetes care, as poor results – indicated by HbA1c levels significantly above target – correlate strongly with the development of complications associated with hyperglycaemia (UK Prospective Diabetes Study Group, 1998). These complications will be discussed in more detail below.

Having the right information about the condition is key to maintaining good health. For this reason, it is essential that the patient and their caregivers attend educational programmes on how to manage the illness from the outset.

Finally, both the NICE guidelines and those produced by the Royal College of Paediatrics and Child Health (2017) strongly recommend that health professionals working with diabetes take account of patients' psychological issues. NICE states that patients "may experience psychological problems (such as anxiety, depression, behavioural and conduct disorders and family conflict) or psychosocial difficulties that can impact on the management of diabetes and wellbeing" (NICE, 2015, p.10).

There is also evidence that acute and chronic stress can affect glycaemic control in patients with T1D and that approaches to reducing stress are key components of diabetes management (Marcovecchio and Chiarelli, 2012).

However, optimal control of T1D is very difficult to achieve in a paediatric population due to a range of developmental and psychological factors (Anderson and McKay, 2011). The logistics of treatment, in terms of regular injections and monitoring of blood sugar, and the risk of acute and long term complications present a challenge for both child and family.

T1D treatment is based on self-management, so its proper implementation depends on patients understanding the different elements of the regimen and what is required of them. In childhood cases, this onus necessarily passes to caregivers, whose own understanding of the illness will therefore play a critical role in establishing appropriate care.

### 1.1.5 Complications

Short-term complications of T1D include hypoglycaemia, diabetic ketoacidosis (DKA) and hyperosmolar hyperglycaemic state (HHS). Longer-term complications include retinopathy, cardiovascular disease, nephropathy and neuropathy (NICE, 2015).

In addition, variations in glucose levels and episodes of hypoglycaemia can lead to vulnerabilities in the developing brain of children with T1D. Studies using MRI show regional reductions in brain volume in certain cases (Biessels and Reijmer, 2014). Evidence has also been found of microstructural changes in white matter regions (Anderson and McKay, 2011; Barnea-Goraly et al., 2014; Seaquist, 2015), reduced grey matter density and reduced activation of the thalamus in response to recurrent hypoglycaemia in patients with T1D (Seaquist, 2015).

Voxel-based morphometry studies (Northam et al., 2009; Perantie et al., 2007) have found associations between a history of severe hypoglycaemia (episodes with unconsciousness or seizures, followed by clinical recovery) and reduced grey matter in the cerebellum, left temporo-occipital cortex and thalamus in children and young adults with long-term T1D.

Complications can also arise from other physical conditions with which the patient presents. The most common of these comorbidities are coeliac disease, thyroid disease, polycystic ovary syndrome, diabetes insipidus, necrobiosis lipoidica diabetorum, mastopathy, muscular conditions and dental health complications (NICE, 2015).

There is also a high prevalence of comorbidity with psychiatric disorders. Given its importance to the current research, this topic will be explored in depth in the following section.

### **1.1.6 Comorbidity with Psychiatric Disorders**

Patients with chronic illnesses are at increased risk of developing psychiatric disorders. It has been found that rates of psychopathology in children with chronic physical illness are up to four times higher than in children who are physically healthy (Green, McGinnity, Meltzer, Ford, and Goodman, 2005; Hysing, Elgen, Gillberg, Lie, and Lundervold, 2007).

Several studies have identified comorbidities between T1D and mental health issues. A cross-sectional survey of a national representative sample drawn from the 2000 UK National Psychiatric Morbidity study found that adults with diabetes (all subtypes) were 50% more likely to suffer from a psychiatric disorder than people without the disease: depression and anxiety were the most common disorders reported (Das-Munshi et al., 2007). When it comes to children, a meta-analysis of 22 peer-reviewed studies comparing diabetic patients with peers unaffected by chronic illness (Reynolds and Helgeson, 2011) concluded that the paediatric population with T1D were more likely than comparison groups to experience a variety of psychological difficulties. The analysis focused on studies assessing depression, anxiety, general psychological distress, psychopathology, behavioural problems (internalizing, externalizing), self-esteem and peer difficulties. It found that children with diabetes reported more depressive symptoms, more clinical depression, more anxiety and more psychological distress than the comparison group.

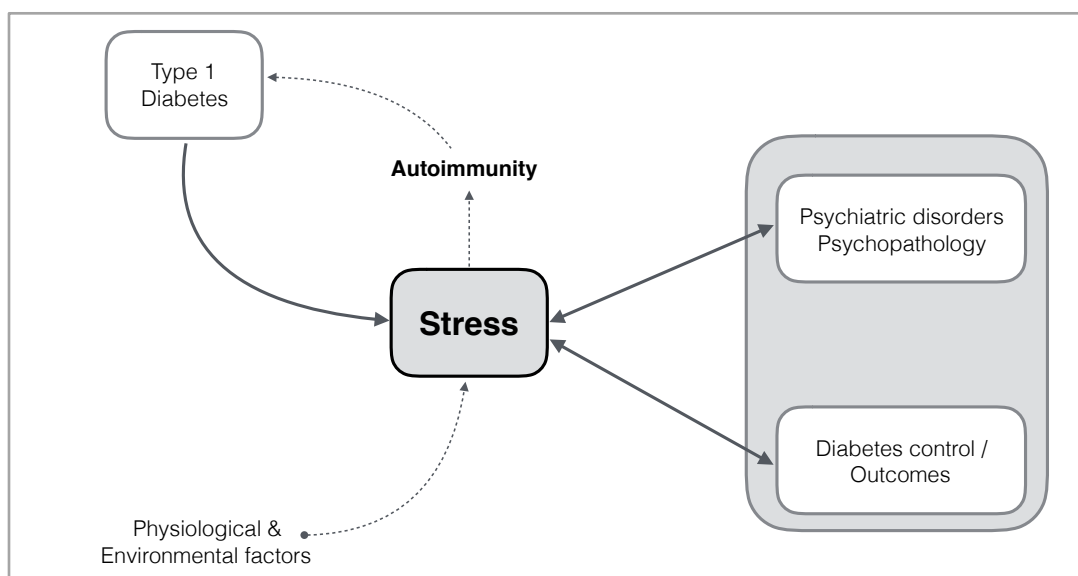
Depression is considered a particularly important comorbidity in diabetes. A study conducted by Anderson and colleagues (2001), for example, found that individuals with diabetes were twice as likely as their healthy peers to suffer from depression (this issue will be discussed on the next page).

In terms of anxiety, one study reported that roughly half of patients with T1D had elevated levels of anxiety (Peyrot and Rubin, 1997). Disturbed eating behaviour is also very common among teenage girls and young women with T1D, with binge eating reported by 45–80% and deliberate induction of glycosuria (reducing the insulin dosage or omitting it altogether to promote weight loss) reported by 12–40% (Fairburn et al., 1991; Jones, Lawson, Daneman, Olmsted, and Rodin, 2000).

These statistics inevitably raise questions about the nature of the causal links between psychopathology and diabetes. Is diabetes a risk factor in the development of psychopathology, or is it the other way around? Or is there, perhaps, a reciprocal relationship between the two?

Considering the available evidence, it can be hypothesized that the relationship between diabetes and psychiatric disorders is reciprocal and that both are mediated by stress (see Figure 1.1).

**Figure 1.1 Relationship between T1D and Psychiatric Disorders**



Diathesis/stress models are particularly helpful in this context (Zubin and Spring, 1977). Used initially to study schizophrenia, these models are designed to help understand how psychopathology comes about. They are often used to investigate susceptibility rather than vulnerability, suggesting that individuals are likely to respond to environmental influences, both positive and negative (see Belsky and Pluess, 2009).

Based on this approach, psychopathology can be understood as a product of genetic vulnerability and environmental stressors. Considering the psychological pain the illness and its treatment can generate, T1D clearly constitutes an environmental stressor and can, therefore, be considered an important factor in the constitution of a psychiatric disorder. The same premise has already informed studies of depression in paediatric patients with chronic illnesses (Burke and Elliott,



1999).

Additionally, since exposure to stress is implicated in the origin of the T1D, it is possible to consider the relationship between T1D and psychiatric disorders in terms of shared mechanisms and origins. As was discussed in the aetiology section, T1D results from an autoimmune process that can be triggered by physiological processes derived from stress.

A study by Moulton, Pickup and Ismail (2015), which looked at the shared mechanisms of depression and Type 2 diabetes, found over-activation of innate immunity in both illnesses, leading to an inflammatory response and, potentially, to dysregulation of the HPA axis. Although the origins of Type 2 diabetes are different to those of T1D (in the former, beta cells remain functional but the body either becomes resistant to insulin or does not produce enough of the hormone, or both), the immune response cited in the above study may be analogous to that implicated in the destruction of beta cells in T1D.

In line with this view, a recent review by O'Connor, Moynihan and Caserta (2014) of studies in psychoneuroimmunology has revealed a significant impact of psychological stress on somatic health in children, mediated by dysfunctions in the immune system.

But while there is emerging evidence of a reciprocal relationship between stress and diabetes, it is also clear that more research is needed. Therefore, the present work does not directly address the issue of causation, as it focuses on children who have already developed the condition. Rather, it investigates the potential role of psychological factors such as attachment and mentalizing in regulating stress-related issues, which may perpetuate and/or trigger mental health difficulties, for

example by exacerbating diabetic symptoms or causing poor metabolic control, leading to short- and possibly long-term complications.

In the following section, the role of stress in the perpetuation and course of diabetes is therefore addressed in more detail.

## **1.2. Psychosocial Perspectives on Diabetes**

As highlighted in the previous section, examining T1D from a psychosocial perspective raises many questions. Although there is considerable research on this dimension of the illness, a comprehensive psychosocial theory of diabetes is still lacking. For this gap to be filled, a better understanding of the psychological impact of T1D in childhood, both at an individual and relational level, is required. This must take account of how typical childhood development is affected by the illness, along with aspects of the patient's mental life most closely related to illness control. The need for such an integrated model is underlined by the fact that studies to date have only explored specific features of the illness, as will be seen in the following pages.

The next section of the literature review seeks to summarize existing knowledge of the psychosocial dimensions of T1D.

### **1.2.1 Psychosocial Factors in T1D**

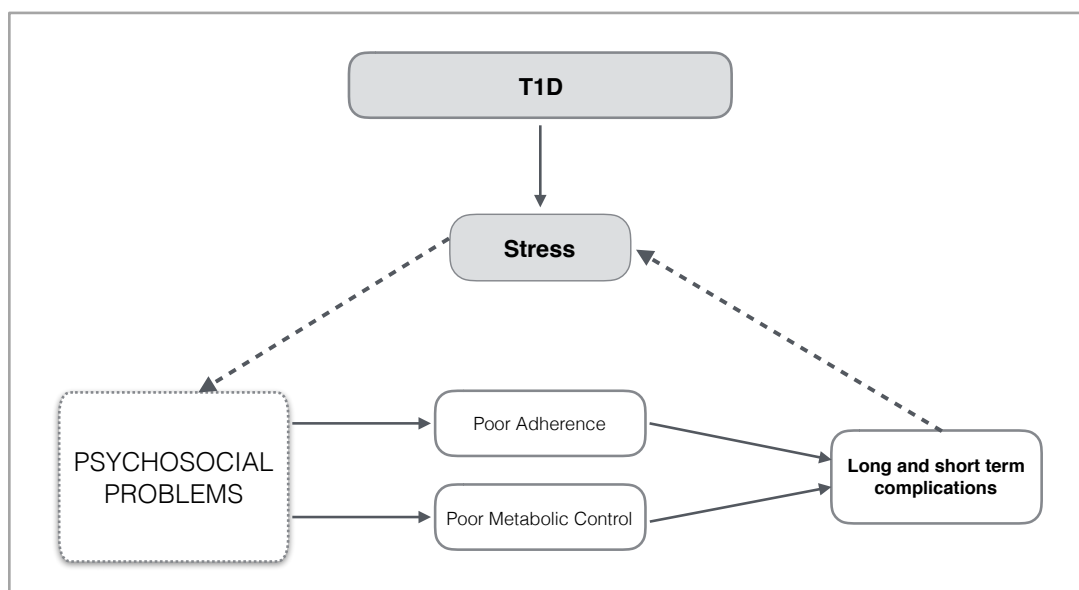
Research on psychosocial factors in T1D has focused on the following areas: (a) the role of psychological factors in the aetiology of the illness; (b) the course of the illness; and (c) its treatment. Studies of the role of psychological factors in the

aetiology of T1D were reviewed in an earlier section, so will not be discussed here. Those looking at the course of the illness tend to focus on the consequences for the patient's mental health of having T1D. Research on treatment and control mainly aims to understand why some patients are better than others at complying with treatment or achieving good metabolic control.

As noted in the previous section, the concept of stress provides a common thread for integrating the various studies of the psychosocial aspects of diabetes. While often not addressed in studies of T1D, the impact of stress on the general psychosocial functioning of children is widely recognized (Patterson, Dahlquist, Gyürüs, Green, and Soltész, 2009; Sepa and Ludvigsson, 2006; Mead, 2004). Consideration of the role of stress is therefore helpful as a first step in developing a more comprehensive approach to understanding T1D from a psychosocial perspective.

Based on the findings of the literature review, the following model is proposed (see Figure 1.2). Because of the threat the illness poses to an individual's survival, T1D and its treatment constitute a significant source of *stress*. This increases the risk of *mental health problems*, which in turn may lead to *poor adherence* and *poor metabolic control*, causing *short- and long-term complications* (for example, retinopathy, kidney failure, heart disease, visual problems). This creates yet more *stress*, leading to a vicious circle. Indeed, T1D in young people has been associated with hypervigilance to bodily states, the need to control food intake, monitoring of blood glucose up to 4-6 times a day, and the need for insulin injections, which are a source of considerable stress. Hence, T1D itself can be seen as an important stressor.

**Figure 1.2. Relationship between T1D and Psychosocial Problems.**



In the section below empirical evidence concerning the relationship between T1D and its various psychosocial dimensions will be summarized.

#### **1.2.1.1 Stress and T1D**

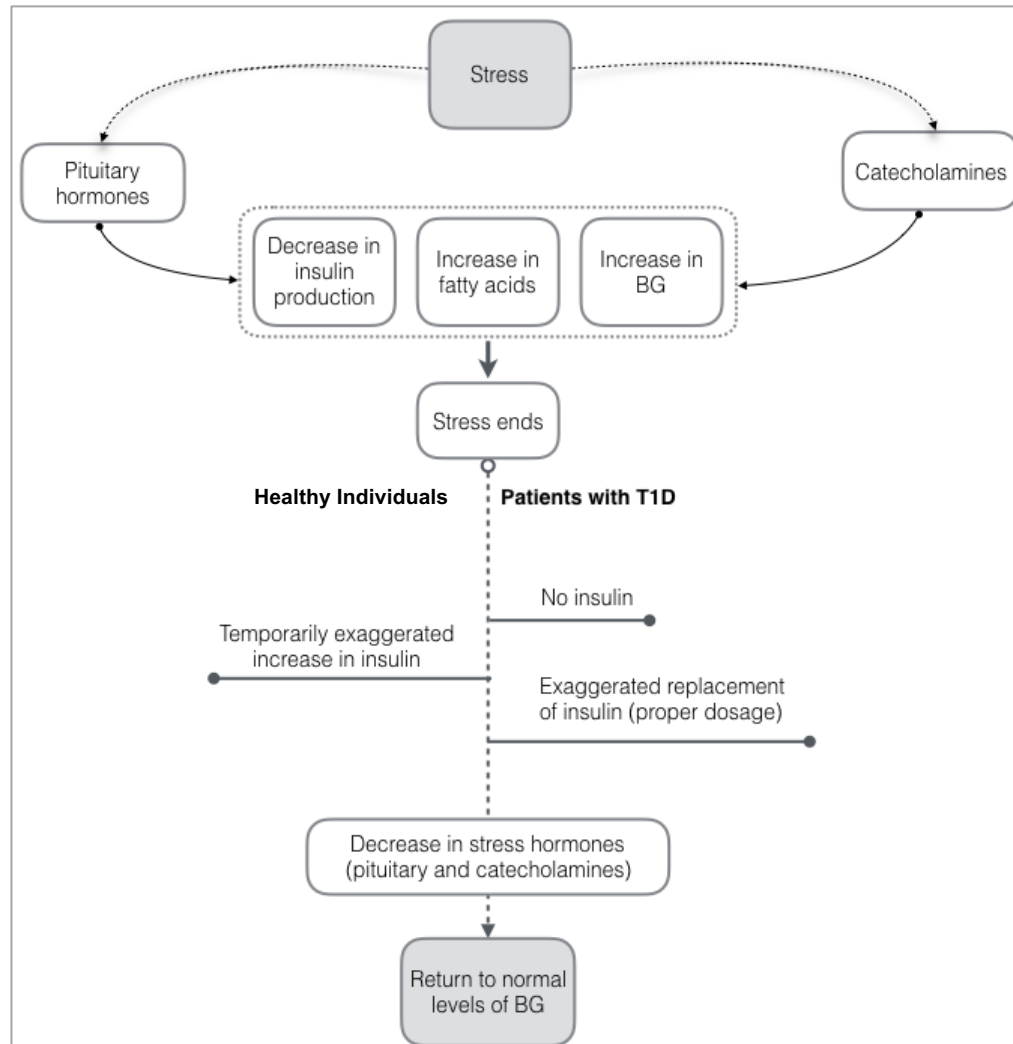
Both chronic and acute activation of stress can have powerful metabolic consequences in patients with T1D (Johnson, 1980). This impact can be direct, through the influence of stress hormones on glucose homeostasis, or indirect, by making the patient less likely to adhere to treatment. In addition, poor metabolic control is thought to interfere with general functioning, exacerbating the effects of various stressors (Fisher, Delamater, Bertelson, and Kirkley, 1982).

Surwit and Schneider (1993) conducted an extensive review of the literature on stress and diabetes. They noted various experimental studies in the 1950s and 1980s in which adults with T1D were subjected to acute stress (mainly noise stress or mental arithmetic and public speaking stressors) to observe its effect on glucose levels. They reported that in the majority of cases stress caused a change in glucose levels in the blood or urine. In some studies, these levels decreased and in others they increased, indicating that psychological stress can have both a hyper and hypoglycaemic effect. While the studies reviewed did not consider differences between individuals at a psychosocial or biological level, they provide some evidence of the relevance of stress to this condition.

The authors note, too, that the mechanism by which stress affects the pathophysiology of T1D is not sufficiently understood and is therefore a crucial area for future research into the role of behaviour in the epidemiology of the condition.

What we do know is that stress has an effect on glucose metabolism (Lloyd et al., 1999; Konen, Summerson and Dignan, 1993). Acute activation of the stress response in healthy people triggers the production of catecholamines and pituitary hormones, which in turn leads to a decrease in insulin production and an increase in blood glucose levels. When stress abates, there is a temporary spike in blood insulin, a decrease in stress hormones and a subsequent return to normal levels of blood glucose, with low free fatty acids. Because patients with T1D have no insulin, they are unable to stabilise the effects of stress hormones in a natural way. The need for an exogenous source of insulin, however, creates an insensitive system, unable to respond quickly or appropriately to fluctuating needs (Efendic, Cerasi, and Luft, 1974) (see Figure 1.3).

**Figure 1.3. Physiological Response to Stress in Normal Individuals vs Patients with T1D.**



The impact of stress on glycaemic control was investigated in a study by Lloyd et al. (1999) of 55 adults with T1D. The authors identified the occurrence of stressful life events and long-term difficulties in the previous 12 months through a semi-structured interview, coded using standardized rating guidelines. They also applied

several standardized measures for self-care, problem-solving, ways of coping and depressive symptomatology. Glycaemic control was assessed through HbA1c measures.

The study found that patients with poor metabolic control were significantly more likely to have reported severe personal stressors, while subjects with proper control were significantly more likely to have reported positive life events during the same period [odds ratio 95%, confidence interval 49.6 (46.9 to 52.3)]. These results support the idea of a negative influence of recent stressful events on glycaemic control.

More recently, Wiesli et al. (2005) measured the effect of acute psychosocial stress on blood glucose levels in adults with T1D. Blood glucose was measured in fasting and postprandial (after meal) states during a normal day and in a stressful situation. In one study, the researchers asked 20 patients to take the Trier Social Stress Test (TSST), which aims to provoke moderate social stress, in a fasting state. In the second study, they applied the TSST to another 20 patients 75 minutes after the intake of a standard meal. Blood glucose concentrations (measured by a continuous glucose monitoring system), blood pressure and heart rate were monitored for both groups. During the preceding day, both the fasting and meal groups were monitored under comparable conditions (daytime measurement of glucose, cortisol and cardiovascular parameters), without stress inducement.

The researchers found that, in the postprandial period, there was a delay in the gradual decrease of glucose concentrations after the onset of stress, whereas in the fasting state there was no change in glucose concentrations between stressful and normal days. These results suggest that, in the postprandial period,

psychological stress can delay the normal decrease in blood glucose levels.

It should be noted that the literature on the influence of stress on glucose metabolism appears to be relatively small. Also, the studies mentioned above have small sample sizes, are cross-sectional and retrospective. Nevertheless, they provide useful evidence of the need to pay closer attention to the impact of stress on this population.

#### **1.2.1.2 Psychosocial Problems in Children with T1D**

It has been suggested that both the onset and the course of T1D can negatively affect mental health. Several studies have consistently demonstrated that children with the illness show more mental health problems and poorer quality of life than healthy children.

The first study that aimed to understand the psychological characteristics of children with T1D was conducted by Swift, Seidman and Stein (1967). They compared a group of 50 diabetic children with a group of 50 matched controls, looking for differences in personality, adjustment and family characteristics relating to the effects of T1D and the relationship between glycaemic control and regulation of the illness. Psychiatric interviews, psychological testing, sociological interviews with parents and, for the experimental group, independent, quantitative ratings of diabetes control were conducted. Each member of the team then wrote an independent report. The study assessed the following areas: self-concept; body image; sexual identification; mode of handling anger; ideas about food and food restrictions; mood; ideas regarding parents and other authority figures; feelings and



patterns of dependence and independence; fears, life goals and life standards of the child; level of anxiety in normal and stress situations; flexibility of personality; feeling tone within the family and general level of maturity. Complete medical reports were obtained from the physicians of each of the diabetic subjects, together with school reports.

The diabetic group was found to have significantly higher levels of psychopathology and showed more extreme ratings of psychiatric classification, dependence-independence balance, self-percept, manifest and latent anxiety, sexual identification, constriction, hostility expression and oral preoccupation.

They also showed increased body image pathology, latent anxiety, constraint, dysphoria and dependency, and significantly worse adjustment at home and with peers. The “emotional tone” of the diabetic home was significantly poorer than that of the control group, with both parents showing more extreme domination-submission behaviour, and mothers exhibiting more extreme protection-neglect behaviour.

Although the above study can be criticized for its small sample size, use of non-standardized measures and the nature of the theoretical constructs it assessed, it remains a highly relevant study in this field in terms of its overall findings and its pioneering focus on psychosocial characteristics in the paediatric diabetic population. Not surprisingly it has been widely cited in the literature on psychology and diabetes.

Another important and frequently cited body of work is that undertaken by Kovacs and colleagues (1986). This group carried out the first longitudinal and prospective study of the impact of T1D on children, involving 95 children (aged from

8 to 13-years-old at study entry), all newly diagnosed with T1D. As an initial step, the researchers analysed the main psychosocial responses of the children during the first year after diagnosis (Kovacs et al., 1986), using targeted semi-structured interviewing and standardized psychiatric tests (self and parental report). The first interview took place 2-3 weeks after diagnosis. This was followed by 3-4 assessments over the first year. The study found that the most common response during that period for the majority of children (64%) was mild sadness, anxiety, a feeling of friendlessness and social withdrawal. Moreover, 36% of the children met the criteria for a psychiatric disorder, which could not be attributed to a continuation or exacerbation of a pre-existing psychiatric condition. The most common of these disorders were adjustment disorder with depressed mood and major depressive disorder, followed by mixed affective syndromes (a mix of depression, anxiety and anger) and anxiety syndromes.

To extend their observations beyond the first year after diagnosis, Kovacs et al. (1990) published an analysis of the longer-term psychological adjustment of these children. They followed the sample for a further 5 years, assessing them once every 8 to 10 months. At each stage, they assessed levels of depression, anxiety and self-esteem with semi-structured psychiatric interviews and standardized self- and parent-report measures. They also used a scale for measuring “issues in coping with diabetes”, developed specifically for the study. They found that increased duration of T1D was associated with increased depressive symptomatology and increased anxiety in girls, but not in boys. Children who showed little depression initially became somewhat more symptomatic over time, while anxious children tended to become more anxious in subsequent years.

The work of Kovacs and colleagues has made a substantial contribution to the field; however, their study is limited because of its relatively small sample size and lack of a control group, making it hard to determine if the psychosocial problems identified were provoked by the diabetes or by broader developmental issues. While they claim that the children in their sample showed no signs of psychiatric issues before diabetes onset, this information was obtained from parental reports only. Truly prospective studies are therefore needed to clarify the role of risk and protective factors involved in the development of psychiatric disorders by patients with chronic conditions *before* onset of T1D.

A similar study, this time with a control group, was carried out by Grey, Cameron, Lipman and Thurber (1995). Using self-report and parent-report measures, these researchers interviewed 89 diabetic children and 53 matched controls at an initial period (within 6 weeks of the diabetic patient's diagnosis) and at 3, 6, 12, and 24 months thereafter. They found no differences in the psychosocial status between the two groups at 1 year post-diagnosis. However, by the end of the second year, depression, dependency, hostility and withdrawal were significantly more prevalent in children with diabetes than in those without the illness. It should be noted that, although this study controlled for developmental issues by matching the diabetic group with healthy peers, the measures used were all self- and parental-report and children were followed for only 2 years. It is not possible, therefore, to separate symptomatology relating to the patient's adaptation period from their more general psychosocial functioning.

A more recent longitudinal prospective study (Northam, Matthews, and Anderson, 2005) followed 133 children after T1D diagnosis, with assessments of

neuropsychological functioning and psychological adjustment at baseline and at 1, 2, and 6 years after disease onset. In terms of psychological problems, assessed by self-report measures, this study found that at the end of the sixth year 37 per cent of subjects met the criteria for a DSM-IV psychiatric disorder. This was two to three times higher than community levels of psychiatric morbidity. Although this study had a longer period of follow-up than that of Grey et al. (1995), the measures used were all self-report and the sample continues to be small for a prospective study.

Finally, the most recent longitudinal study, with the biggest sample in this field, was conducted in Sweden by Butwicka, Frisén, Almqvist, Zethelius and Lichtenstein (2015). The aim of the research was to assess the risk of psychiatric disorders in children with T1D. In the study, 17,122 children with T1D and their 18,847 siblings (from a population-based case-cohort study of individuals born in Sweden between 1973 and 2009) were followed to the age of 18. The researchers took data from the Swedish Paediatric Diabetes Quality Registry and the Swedish National Diabetes Register, which contain information about the diabetic population, and matched this with data from the Swedish National Patient Register of psychiatric disorders. They also investigated the mechanism behind the association between T1D and childhood psychiatric disorders by studying psychiatric outcomes in full siblings of patients with T1D (i.e. children of the same parents without a diagnosis of any type of diabetes).

The study found that psychiatric morbidity tripled within 6 months of a T1D diagnosis (hazard ratio, HR, of 3.0, 95% CI 2.7–3.4) and doubled within the total observation period (HR 2.1, 95% CI 2.0–2.2). Specifically, psychiatric disorders were recognized in 1,428 (8.3%) of diabetic patients, of whom 259 had more than one disorder. Adjusting for sociodemographic and perinatal factors, these patients were

2.1 times more likely to receive a psychiatric diagnosis and 1.7 times more likely to attempt suicide than control subjects. They also had an increased risk of mood disorders (HR 2.0, 95% CI 1.8–2.3), anxiety disorders (HR 1.6, 95% CI 1.4–2.0), eating disorders (HR 2.2, 95% CI 1.8–2.6), substance misuse (HR 2.6, 95% CI 2.4–2.9), attention-deficit hyperactivity disorder (HR 1.5, 95% CI 1.3–2.7), behavioural disorders (HR 2.2, 95% CI 2.0–2.4), autism spectrum disorder (HR 1.7, 95% CI 1.4–2.0), and intellectual disability (HR 1.8, 95% CI 1.5–2.1) compared with healthy peers.

Overall, the authors concluded that diabetes increases the risk of psychiatric disorders, but that the comorbidity between conditions is complex. They also suggested, based on their sibling data, that diabetes and psychiatric disorders may lack a shared genetic susceptibility (thereby challenging previous assumptions).

This study is highly relevant to the present work as it demonstrates, once again, the value of studying diabetes from a psychosocial perspective. Moreover, of the studies reviewed, it is the strongest in terms of its sample size and longitudinal design. One limitation, however, is its use of a register-based methodology, which can potentially bias the data on psychiatric disorders in children with T1D. Also, the diagnoses in these cases were probably made by diabetologists who had been continuously assessing the condition of each child, whereas healthy peers would have had their psychosocial state assessed far less frequently. However, the study controls for several possible confounders, has a follow-up period stretching to adulthood and has a very large sample size.

### **1.2.1.3 Other Psychosocial Problems**

An area of research not scrutinized in detail by this review is the relationship between specific childhood psychiatric disorders and T1D. The majority of studies in this field have focused on depressive symptoms (Plener et al., 2015). This is probably due to the prevalence of such symptoms within the diabetic population: it has been claimed that 20-25% of children and adolescents with T1D suffer from depression (Grey, Whittemore, and Tamborlane, 2002). The next most studied category comprises anxiety disorders, especially diabetes-specific variants such as “specific phobia of needles” (Cemeroglu et al., 2015; Howe, Ratcliffe, Tuttle, Dougherty, and Lipman, 2011) and “fear of hypoglycaemia” in children (Cox, Irvine, Gonder-Frederick, Nowacek, and Butterfield, 1987; Hawkes, McDarby, and Cody, 2014). The third most common are eating disorders. The prevalence of such disorders among patients with diabetes is estimated at around 18% (Danoiu, Danoiu, Danciulescu Miulescu, Poiana, and Cristescu, 2010). It is suggested that certain aspects of T1D treatment make patients particularly vulnerable to this type of illness (Peterson, Fischer, and Young-Hyman, 2014): for example, refusing to take insulin can induce glucosuria that in turn leads to weight loss.

Another group of excluded studies, dating mostly from the 1960s and 1970s, are those which sought to understand the then-popular concept of the “diabetic personality” (the 1967 study by Swift and colleagues cited above, for example, noted that sufferers of the illness showed an “orally-fixated personality type”). Most assumed that traits of this kind were a consequence of the patient’s reaction to the illness. However, others, such as the one by Stein and Charles (1975), based on an in-depth analysis of 8 cases of children with T1D (8 to 18-years-old), hypothesized

that the features of the “diabetic personality” were rooted in early childhood. Although worth mentioning, these theoretical claims are no longer taken seriously.

As can be seen from the studies summarized above, the focus nowadays is on the symptomatology of diabetes-related impacts and on developing more measurable constructs, with the presumed aim of placing the research field on a firmer scientific footing. However, perhaps because of its attempt to develop a more evidence-based approach, this body of research tends to focus on measuring specific constructs in specific populations, and as a result appears fragmented. There is an absence, in particular, of a solid model of subjectivity and development and of analysis that considers different dimensions of the human experience. This should not surprise us, as there is as yet no integrated theory on which to build such a model.

In summary, the bulk of the scientific evidence supports the notion of children with T1D being a risk population for the development of psychiatric disorders. Although most studies differ in their methodologies, and a few provide evidence based on longitudinal and prospective methods, all show similar results regarding the prevalence of this link. However, the studies reviewed in this section do not properly consider the developmental issues at play in the course of the child’s illness. Some have also analysed children with a wide age range, without considering the fundamental differences at each developmental stage in the subject’s psychosocial (achievement of autonomy, relationship with peers) and physiological (hormonal) status.

#### **1.2.1.4 Psychosocial Problems in Families of Children with T1D**

Research on the impact of T1D on the family of children with T1D broadly supports the claim that T1D should be studied and conceptualized from an interpersonal perspective. The dynamics of a child's social (and, in particular, family) life affect not only the course of illness but potentially the life and wellbeing of other family members. This body of research suggests that T1D affects different family members in different ways, as well as impacting family function as a whole. However, the theoretical basis of these studies does not constitute a relational perspective *per se*, as they do not consider the subject's mental development within a relational setting, or try to explain the mechanisms underlying the relationship between family variables and the child's diabetes. In particular, they do not adopt a specific psychological model for understanding the diabetic child in the context of their primary relationships.

It is, however, well demonstrated that T1D may have a considerable impact on the child's family. Several studies confirm the high risk of disruption in families of children with T1D (Burroughs, Harris, Pontious, and Santiago, 1997; Fonagy, Steele, Steele, Higgitt, and Target, 1994; Jacobson et al., 1997; Johnston and Marder, 1994). After a T1D diagnosis, it is also very common for parents of the diabetic child to develop anxiety, depressive symptoms and stress (Horsch, McManus, Kennedy, and Edge, 2007; Landolt et al., 2002; Northam, Anderson, Adler, Werther, and Warne, 1996; Streisand et al., 2008), including symptoms of posttraumatic stress disorder (PTSD) (Horsch, McManus, and Kennedy, 2012). Indeed, it is estimated that 24% of mothers and 22% of fathers of children newly diagnosed with T1D suffer from PTSD (Landolt et al., 2002). Also, siblings of diabetic children have been shown



to exhibit significant levels of psychological stress and anxiety (Hollidge, 2001).

Another common problem for parents of diabetic children is poor sleep quality, mainly related to worries about hypoglycaemia and the night-time management of their child's illness (Herbert, Monaghan, Cogen, and Streisand, 2015).

The above evidence is supported by the findings of a systematic review by Whittemore, Jaser, Chao, Jang, and Grey (2012) of 34 studies of parental psychological factors in parents of children with diabetes. The review found that the prevalence of parental psychological distress across these studies ranged from 10% to 74%. In one study, which focused specifically on stress among parents of children with T1D (Moreira, Frontini, Bullinger, and Canavarro, 2013), parents reported feeling anxious and distressed about their own parenting abilities. The study compared 88 families with a child with T1D with 121 families with healthy children. Through self-report measures, it assessed levels of family cohesion, parenting stress and depression/anxiety symptoms among parents, along with the quality of life of the children. The most significant difference between the two groups was in the level of parental stress.

While these parental problems constitute an important health issue in their own right, some studies suggest they also have a significant bearing on the wellbeing of the children involved. Indeed, parenting stress has been shown to be one of the strongest determinants of psychosocial problems in children with diabetes (Drotar, 1997; Hilliard, Monaghan, Cogen, and Streisand, 2011; Kovacs, Goldston, Obrosky, and Bonar, 1997).

The psychological implications for mothers have been studied separately. Three studies showed that mothers of children with diabetes had higher

preoccupation and lower quality of life than the children's fathers (Hansen, Weissbrod, Schwartz, and Taylor, 2012; Jönsson, Lundqvist, Tiberg, and Hallström, 2015; Wennick and Hallström, 2007).

In line with these findings, a qualitative study by Sullivan-Bolyai (2003) found that the most common preoccupation among mothers was the need for "constant vigilance" as a strategy to meet the daily demands of diabetic management. Mothers described their hypervigilance to the signals of diabetes as akin to caring for a newborn baby. This vigilance was generally marked by fear and anxiety; however, mothers also identified the burden of care as the cause of problems such as depression, migraines and weight variations.

A qualitative, longitudinal study conducted by Lowes, Lyne and Gregory (2005) carried out 40 in-depth interviews with parents of 20 children with newly diagnosed T1D. These interviews were conducted within 10 days of diagnosis and 4 and 12 months after diagnosis. The researchers found that an important aspect of the experience of parents with children with T1D across the study period was the loss of spontaneity in everyday life and the continuing fear of hypoglycaemia, especially at night. Parents also spoke of a lack of confidence in their diabetes management skills, even at the 12-month stage, and of feeling confused and not in control when faced with inexplicably high or low blood glucose measurements.

Similar findings are presented in another qualitative study by Hatton, Canam, Thorne and Hughes (1995), consisting of multiple interviews with the family members of 8 children with T1D over a 5-month period. The parents interviewed described their high preoccupation after diagnosis and their fear of not being able to

provide a proper level of care, commenting that the experience of interpreting and managing their child's blood glucose levels was particularly stressful.

Interviewees also spoke of their intense fear, anxiety and frustration when faced with the lability of their child's condition (i.e. rapidly fluctuating blood sugar levels, erratic mood swings and inevitable confrontations over food and invasive procedures) and the realization that they could not always control these variables, especially in the early phases of the disease.

In summary, qualitative studies in this area provide valuable, detailed information about the parental experience of living with children with T1D. However, while their insights go further than those of purely quantitative studies, they have not yet been integrated into a coherent model or theory or reconciled with broader conceptions of human subjectivity.

#### **1.2.1.5 Psychosocial Factors in Adherence/Self-Management and Metabolic Control**

Psychosocial problems in children with T1D and their families can be viewed as a complication in their own right; but as will be seen in what follows, they are also associated with poor adherence to treatment and poor glycaemic control, both of which increase the risk of further complications (see Figure 1.2). It is possible that several psychosocial factors are implicated in this relationship. If so, these have not been comprehensively studied, as will also be explained below.

When speaking about adherence to treatment or self-management, we are referring to the way in which the patient undertakes the management of their

condition, which in T1D is often complex and demanding. This aspect of the condition is highly relevant because, unlike with other paediatric conditions, treatment is essentially self-managed. Indeed, the terminology “adherence” and “compliance” is being gradually replaced by “self-management” in T1D care, emphasizing the care patients provide for themselves, with the help (but not active involvement) of health professionals (Schilling, Grey, and Knafl, 2002). As was mentioned in Section 1.4 on T1D management, this requires constant attention to and monitoring of BG levels and carbohydrate intake on the part of the child and their parent, as well as frequent insulin administration, with dosage varying according to the level of physical activity and food consumption, among other factors.

Metabolic control is the main treatment outcome in the management of diabetes. An effective control regime is one that keeps blood glucose levels as close as possible to those of a healthy person. The standard measure for metabolic control is HbA1c which, as mentioned previously, indicates the average blood glucose level over a 2 to 3-month period. It is generally assumed that the level of control is directly related to the patient’s success in managing his condition (Guo, Whittemore, and He, 2011); however it is also known that factors beyond the patient’s control can lead to metabolic dysregulation (such as viral infections or difficulties in detecting endocrinological interactions), as can socio-demographic factors such as ethnicity, family involvement and age (Guo et al., 2011).

A number of studies have sought to explore the relationship between psychosocial factors and both adherence to treatment and metabolic control. In most cases they show that patients with the highest rates of psychosocial problems are those with the lowest adherence to treatment and poorest metabolic control. They

also confirm that psychological factors have an impact on long-term control, either through neuro-hormonal mechanisms or through their impact on a youngster's motivation and ability to comply with treatment (Daviss et al., 1995; Helz and Templeton, 1990).

## **Self-Management**

For the most part, studies of the relationship between self-management and psychosocial factors have tried to understand why some patients manage their condition better than others, by looking for specific associations between one (or sometimes more than one) psychosocial factor (like depression or anxiety) and poor or good self-management, with no real explanation offered as to the nature of this association (i.e., within a psychological model). Despite this limitation these studies generally support the idea that adherence to the treatment needs to be addressed from a psychosocial perspective.

Some (but only a few) studies have looked at how children manage their condition from a psychosocial perspective. For example, it has been shown that children showing high levels of externalizing behavioural problems are less successful at self-management than their peers and experience worse glycaemic control both in current (Duke et al., 2008) and later life (Bryden et al., 2001).

Depression is the most studied variable in terms of self-management in children with T1D. A meta-analysis by Kongkaew, Jampachaisri, Chaturongkul and Scholfield (2014) of 19 prospective observational studies examined the association between depression and treatment adherence in paediatric patients. The authors found that depression was moderately associated with non-adherence to treatment

in diabetic children, based on patient self-report measures. The effect size was 0.22, suggesting that depression might be one of the underlying factors that compromise self-management in T1D.

The majority of research in this area focuses on adolescence, a period in which self-management tends to be most neglected (Greening, Stoppelbein, and Konishi, 2006; Leonard, Jang, and Savik, 2005). In such samples, the support of friends has been linked to better adherence (Skinner and Hampson, 1998), as has greater commitment to specific aspects of self-care, such as more frequent blood glucose monitoring (Bearman and La Greca, 2002). A review conducted by Martinez, Frazer, Dempster, Hamill, Fleming and McCorry (2016) examined 21 studies of the relationship between diabetes self-management and a range of psychosocial variables, both emotional (specifically anxiety, depression, fear of hypoglycaemia and stress) and cognitive (self-efficacy, motivation, illness representation). The authors pointed to the difficulty of conducting their analysis: not only did the studies in question measure different variables, even where these variables were similar, the studies used very different, often non-standardized, assessment tools. That said, the majority of studies reported a significant relationship between one or more emotional and/or cognitive variable and self-management (measured in terms of frequency of BG levels monitoring), again supporting the role of psychosocial factors in adolescent self-management.

It should be noted that the present research focuses not on adolescence but on childhood. Few studies have addressed the issue of self-management in this age group from a psychosocial perspective. This is an important gap, as we know that children report enormous difficulties in detecting the rise and fall of BG levels. It has

also been argued that school-age is the period when the foundations of self-care are established (Kelo, Martikainen, & Eriksson, 2011).

Self-management in childhood is a practice the child acquires and incorporates into his life gradually. Taking proper responsibility in childhood for the illness (performing tasks appropriate to the child's age and skills) is likely to help in the critical "transfer phase" (transferring treatment responsibility from parents to the patient), which typically takes place during adolescence. A significant cause of non-adherence during adolescence is believed to be the inappropriate transfer of disease-related control from parent to adolescent (Gowers, Jones, Kiana, North, and Price, 1995).

Other studies, which analyse management issues in the paediatric population, look for an association between psychosocial family factors and adherence to treatment. These studies generally assess family conflict and family support. For instance, some report that family support is related to better adherence and better metabolic control (Burroughs et al., 1997) and is predictive of better future adherence to treatment (La Greca, Swales, Klemp, Madigan, and Skyler, 1995).

A number of studies have set out to explore how family functioning can impact the willingness and ability of children to take responsibility for their condition. A review of this literature by Pérez, Gomez, and Montoya (2015) found that the proper acquisition of autonomy was impaired by excessive family cohesion, overprotective parenting and the enforcement of rigid rules and strategies. By contrast, families who achieved a smooth transition were characterized by the promotion of autonomous behaviour. These families were better able to transfer responsibilities of care to their child, and to help him reach satisfactory self-management. This was

particularly common in cases where children had previously taken a degree of responsibility for their own care (Hanna, Dashiff, Stump, and Weaver, 2013).

Scientific evidence has been unable to distinguish with clarity which aspects of the patients' psyche are most important to managing their condition. In general, studies in this field look only for associations between family features and adherence to treatment or illness management: none of them explores how this process actually happens.

### **Metabolic Control**

In terms of metabolic control, a significant study is that of Helgeson, Siminerio, Escobar and Becker (2009), who followed 132 children and adolescents with T1D over a 4-year period. They examined the role of self-care behaviour and other “risk and resistance” variables associated with metabolic control – such as depression (“risk”) and family support (“resistance”) – in each of the 4 years of assessment. They also assessed if these factors predicted changes in metabolic control over the study period (for more information on the risk and resistance framework in chronic illnesses, see Wallander, Varni, Babani, Banis, and Wilcox, 1989 and Wallander and Varni, 1992, 1998). Children were interviewed and assessed using standardized self-report measures for depression and eating disturbances immediately after diagnosis, and 1, 2, and 3 years after diagnosis. The study found that depressive symptoms predicted deterioration in metabolic control over time and that disturbed eating behaviour was a risk factor in poor self-care, which also had implications for metabolic control.



Several studies have revealed a significant connection between family functioning and metabolic control. Patients reporting high levels of family conflict tend to show worse metabolic control and poorer adherence to treatment (La Greca and Mackey, 2009; Miller-Johnson, Emery, and Marvin, 1994; Sander, Odell, and Hood, 2010). By contrast, a family environment characterized by high cohesion, good communication and low conflict was associated with better metabolic control in a study conducted by Naar-King, Podolski, Ellis, Frey and Templin (2006).

A systematic review of 10 studies assessing the relationship between diabetes-related conflict and HbA1c (Tsiouli, Alexopoulos, Stefanaki, Darviri, and Chrousos, 2013) also found that family conflict correlated negatively with glycaemic control. Indeed, in one of the studies reviewed (Lewin et al., 2006), family function variables (such as family conflict and family cohesion) explained 34% of HbA1c variance.

Grabill et al. (2010) applied several measures relating to family conflict, diabetes-specific worries, depressive symptoms and glycaemic control (HbA1C) to 147 adolescents and their caregivers (three times, over a 9-month period). Their analysis showed that anxiety was the only factor to mediate between family conflict (reported by the caregiver) and glycaemic control. They concluded that anxiety is likely to be more common in families experiencing conflict, and that this can in turn have direct effects on glycaemic control.

These findings must be treated with caution, as the relationship between different psychological variables is highly complex. For example, while peer support has been associated with better control in adolescence (Wysocki and Greco, 2006) a recent study found it can also lead to poor glycaemic control if it is perceived by

the adolescent as a threat to his autonomy (Doe, 2016). Again, a unifying theory, incorporating a complete psychological model of the diabetic subject, could be helpful in interpreting these findings.

Also, even if we accept that high levels of family conflict are likely to occupy a big part of the mental space of each family member, and may lead to failures in the regulation of anxiety, it is difficult to derive firm conclusions from these studies, as they use different instruments to measure both anxiety and family conflict. They also suffer from the methodological drawback of using self-report measures to explore relational phenomena. The results of this research would conceivably be very different had the exploration of relational issues (such as family conflict) involved observation of actual interactions rather than capturing the perceptions of individual family members regarding these complex and intimate relationships.

Nevertheless, these studies provide very relevant information about the bi-directionality of the association between diabetes and family functioning. They also confirm the value of analysing the relationship between stress regulation and metabolic control, which is a key element of the current study.

An issue that has yet to be addressed is the considerable variation in both metabolic control and self-management problems within the diabetic population, and the reasons for these differences. For example, the psychological development of the diabetic subject has not been considered properly in terms of models and theories with therapeutic implications. Significantly, none of the studies reviewed above has been used to design proper psychosocial interventions. This may explain why the psychosocial interventions developed to date have not proved particularly effective, as will be seen in the next section.

### **1.2.2 Psychosocial Interventions with Diabetic Patients**

A range of interventions based on psychosocial perspectives have been attempted to help patients with T1D deal with their condition (Ducat, Rubenstein, Philipson, and Anderson, 2015; Jones, Vallis, and Pouwer, 2015). While most of these aim to improve self-management and metabolic control, some also directly address psychological problems such as depression and anxiety. Interventions of this kind have been shown to slightly improve HbA1c levels and decrease some diabetes-specific psychological distress (Hampson, Skinner, Hart and Storey, 2000). However, besides the fact that they mainly target change at a behavioural level, they have not been able to properly demonstrate their effectiveness and are not well rooted in theory.

A meta-analysis and systematic review by Winkley, Landau, Eisler and Ismail (2006) of a wide range of psychosocial interventions involving patients of different ages (i.e., children, adolescents and adults) identified 21 randomized controlled trials (RCTs), including 10 of interventions for children and adolescents with T1D. The study assessed whether psychosocial interventions led to improved metabolic control (as measured by a reduction in HbA1c) and decreased psychological distress (assessed using different measures across the studies). The interventions evaluated included Supportive or Counselling Therapy, Cognitive Behavioural Therapy, Psychoanalytically-Informed Therapy and Family Systems Therapy. Data from all interventions involving children showed reductions in glycated haemoglobin of 0.48% (0.05 to 0.91%) for children and adolescents. Sensitivity analysis showed that

family therapies slightly increased the pooled standardized effect of therapy for children and adolescents ( $d=.41$ ,  $-.79$  to  $-.03$ ;  $p=.03$ ).

In terms of psychological distress, the 10 analysed studies reported an improvement overall. However, the pooled estimate of the mean therapy effect on psychological distress for children and adolescents was only moderate (standardized effect size  $-.46$ ,  $-.83$  to  $-.10$ ,  $p=.013$ ). The authors pointed out that the methodological quality of most studies was moderate to poor and that, taken as a whole, the evidence for the effectiveness of psychological treatments in improving glycaemic control was weak.

In a review article, Northam, Todd and Cameron (2006), having looked at 14 studies of psychosocial interventions for patients with T1D, concluded that the major component of these interventions was increased contact and support, psychoeducation and/or cognitive behaviour techniques to promote behaviour change around diabetes management. None of the interventions addressed underlying feelings of anger or dysphoria, for example. Also, it is remarkable that very few interventions were tailored to children, for whom preventive interventions could be very helpful. Finally, the authors found that the interventions reported were generally unstandardized and unreplicable, and only vaguely rooted in theory.

Concerning the theoretical roots of these interventions, a very interesting study is that of Ayling, Brierley, Johnson, Heller, and Eiser (2015), who analysed 27 RCTs of T1D theory-based behavioural change interventions. They found that 30% of the studies did not, in fact, cite any kind of theoretical approach for the intervention. Where they did, it was only to demonstrate that a particular theoretical construct predicted the patient's behaviour. The pooled effect sizes were marginally larger for

trials that used theory in some way compared with those who did not ( $d = .22$ , 95% CI = .07–.36 for the theoretical studies versus an effect size for the remaining studies of  $d = .12$ , 95% CI = -.14 to .37).

A systematic review of the literature by Hampson and colleagues (2000) produced similar results. The review assessed the effectiveness for adolescents with T1D of behavioural interventions designed to increase self-management, metabolic control and psychosocial problems. It calculated the effect sizes of 18 interventions evaluated in RCTs. The overall mean effect size across all outcomes was  $d = .33$  (median .21), indicating that the interventions had a small-to-medium-sized beneficial effect on diabetes management. The review also found that interventions with a theoretical basis were significantly more effective than those without ( $p < .05$ ). The authors noted that the studies reviewed were very poor in certain methodological aspects (for example, using unrepresentative samples and unstandardized measures).

Only two studies of Cognitive Behavioural Therapy (CBT) for children with T1D were found in the present literature review. The first, by McGrady and Hood (2013), involved the treatment of 9 adolescents, aged between 13 and 18, suffering from T1D and subclinical symptoms of depression. These patients were assessed after their participation in 12 individual sessions based on an adaptation of the Treatment for Adolescents with Depression Study method (March et al., 2004) which focused on diabetes-specific negative thoughts, diabetes burnout and negative effects relating to BG monitoring. Using self-report measures, the researchers evaluated depression and diabetes among participants and their caregivers prior to study entry and following participation. Adolescents completed the Children's Depression Rating

Scale-Revised (CDRS-R) and Diabetes Self-Management Profile (DSMP). Caregivers completed the CDI-Parent Version (CDI-P) and DSMP parent-report. HbA1c was used as the measure of metabolic control. The authors stated that the intervention was effective at increasing self-management and decreasing depressive symptoms but did not report an effect size.

The second paper, reporting on a CBT intervention with adolescents with T1D (Rosselló and Jiménez-Chafey, 2006), presented the results of group therapy aimed at decreasing depressive symptoms and increasing metabolic control. A total of 11 patients, aged from 13-16, took part in 12 sessions. Each was assessed pre and post intervention for depressive and anxious symptomatology, self-esteem, hopelessness, self-efficacy and self-control using the following self-report measures: Beck Anxiety Inventory (BAI), Hopelessness Scale for Children (HSC), Piers-Harris Children's Self Concept Scale (PHSCS), Summary of Self-Care Activities (SSCA), Self-Efficacy for Diabetes Scale (SED) and HbA1c for metabolic control. The authors reported that self-concept and self-efficacy significantly increased after the intervention and that hopelessness, depression and anxiety decreased. However, again, they did not mention an effect size or quantify the extent to which the intervention had been effective.

Both CBT studies suffer from the same problems, namely unrepresentative samples, no reported effect size, no control group and no long-term follow-up. These problems are very common in the field of psychosocial interventions for T1D children: even where their target population and therapeutic aims are similar, they use different measures for assessing their interventions, making it more difficult to evaluate and integrate the evidence.

The impact of family-oriented interventions has also been documented. In a systematic literature review by McBroom and Enriquez (2009), 9 studies were found involving RCTs of family-centred interventions. All focused on improving metabolic control in children and/or adolescents using the HbA1c measure, with follow-up at 3, 6, 9-months or similar. The authors only summarized the results of the interventions, which they concluded had improved metabolic control, reduced diabetes-related conflict and improved family relationships. As the review did not report effect sizes for any of the studies, it is not possible to verify the effectiveness of these treatments.

Even where studies in this field have reported the effects of their interventions in a stronger methodological way, for example through RCTs, other problems have emerged. One of these relates to the definition of “standard care” used in the analysis. In a review of 20 RCTs of behavioural-change interventions for youngsters with T1D, Ayling et al. (2015) found that the information reported by studies regarding “standard care” was very limited (in some cases it was not reported at all), making it impossible to determine which techniques were used in the control groups. Even allowing for this, the authors found considerable variation in the standard care provided. On examining the effect of this variation on control group outcomes they concluded that the effect sizes calculated for interventions would alter significantly if the quality of the standard care were considered in the analyses: interventions compared with higher standard care quality would appear less effective than if compared with lower quality standard care. This finding calls into question the validity of RCTs for testing the efficacy of health behaviour change interventions. One could therefore conclude that the general effectiveness of psychosocial interventions for young people with T1D is still largely unknown.

There are many other relevant factors that interventions have overlooked. One is the patient's age. It is not enough to target "children" or "adolescents": each age has its own particularities, and in diabetes these are highly relevant. Indeed, at the last major conference on diabetes and mental health (in 2015), a working group was formed to discuss ways to improve interventions in this area. One of its main conclusions was that mental and behavioural health issues facing young people with T1D must be addressed within a developmental framework, giving careful consideration to the particularities of different stages of child development (Ducat, Rubenstein, Philipson, and Anderson, 2015). It is also important to note that the majority of psychosocial interventions in this population have as their first aim the improvement of HbA1c levels. However, it is argued that better metabolic control should not be their only goal. Jones, Vallis and Pouwer (2015), for example, claim that the achievement and maintenance of psychological well-being must also be seen as a positive outcome in diabetes care, as tackling diabetes-related distress has been shown to enhance diabetes control.

In conclusion, it is clear that there is an urgent need for carefully conceived interventions for this population. At present, there are few interventions for children based on a detailed psychological perspective of diabetes. Those on offer tend to be adaptations of more general treatments, developed with only partial consideration of evidence relating to diabetic patients. To give an example, since patients are known to suffer from "diabetes distress", interventions to address this problem may claim to be "diabetes-specific", even though the basis of those interventions overlooks fundamental aspects of the psychological development of the person with the disease.



Diabetes management undoubtedly has an important behavioural component, which represents an obvious burden for the psychological development of the subject. It is clear that psychology has a very important role to play in helping this population. Yet to date, this requirement has not been fully recognized by the discipline. In particular, the lack of a proper theory means that no intervention has yet been shown to be clearly effective.

Moreover, the fact that documented interventions do not consider deeper psychical aspects of the disorder is a big problem. They do not, for example, consider properly the affective and relational context in which the child develops, which is crucial to their emotional regulation. It is very likely that closer consideration of these aspects of the human psyche will lead to improved results. For example, the work of Fonagy, Moran and colleagues shows that psychological interventions with T1D children can significantly modify BG levels. Moran, Fonagy, Kurtz, Bolton and Brook (1991) demonstrated that a psychoanalytic intervention of 3 to 4-times-a-week sessions for a period of 12 weeks in a group of children with T1D with very high levels of BG and recurrent hospitalizations was significantly successful in improving metabolic control, and that this improvement was maintained after a year on follow-up. The authors stated specifically that the verbalization of conflict may have had a positive impact on the regulation of metabolism. These findings reveal the fundamental role of inter- and intrapsychic elements. It may be that putting their conflicts into words within the context of a psychotherapeutic relationship helped these patients to improve certain aspects of their bodily functioning, apparently outside conscious awareness.

Work such as this is very important to the present research. Along with related studies, it will be considered in more detail in the next chapter, where current work on attachment and diabetes will be outlined, along with a contemporary psychodynamic perspective of attachment and mentalizing in relation to diabetes.

### **1.3 Conclusion**

The psychosocial dimension of T1D in children is fundamental to determining the course of the illness, as the evidence summarized in this chapter clearly demonstrates. However, an understanding of the psychological impact of the illness in childhood, both at an individual and relational level, is required for a unified theory to be developed.

The aim of this thesis is to integrate current knowledge on this subject with core features of a contemporary psychodynamic perspective, giving special consideration to an attachment-mentalizing perspective in order to develop a comprehensive model for understanding the impact and course of diabetes within the mother-child dyad.

Therefore, in the next chapter the literature concerning both classic and contemporary psychodynamic perspectives on T1D will be discussed, to introduce the theoretical roots of the model that the present thesis pretends to test, and that will be presented at the end of the chapter.

## **Chapter 2**

### **Type 1 Diabetes from a Psychodynamic Perspective: A Review of the Literature**

#### **Introduction**

Chronic conditions have long been an object of interest to psychodynamic therapy and research because of the unique opportunity they offer to study the highly complex relationship between psyche and soma (Marty, M'Uzan and David, 1963; Taylor, 1987; McDougall, 1982 and 1989).

In childhood, where developmental aspects add to this complexity, the body of knowledge is more limited. However, there is crucial work linking psychodynamic theory to diabetes research that, together with studies of similar conditions, provides the basis for developing a contemporary psychodynamic model for understanding Type 1 diabetes in childhood.

This chapter presents a review of the literature concerning psychodynamic perspectives and Type 1 diabetes (T1D). It lays the foundations for the integrative approach that guides the empirical studies which I will present in the second part of this thesis.

The present chapter is divided into three sections. The first describes traditional psychoanalytic approaches to T1D: the body of theories that focus on the unconscious, rooted in the work of Freud and his followers and based on intensive clinical observation and interpretation of subjective experience. The main concepts in these works are reviewed and discussed, including aspects of diabetes that affect

an individual's psyche, and aspects of the psyche that affect diabetes management. These include the incorporation of diabetes into a child's psychic life – with all the attendant traumas for both child and caregiver. For example, the regression of the child to earlier developmental phases and the consequent renegotiation of key elements of somatic and disease regulation, such as through body-self and self-food relationships. In addition, the role of defence mechanisms, the “regulating object”, and the therapeutic relationship in diabetes management will be presented. The theoretical and methodological limitations of these studies are discussed at the end of this section.

In the second section, a discussion of the work of Peter Fonagy and George Moran on T1D (1987- 1994) is presented. Fonagy and Moran proposed a systematic approach to the study of the effect of psychoanalytic treatment on children with T1D who were experiencing severe problems with metabolic control. By demonstrating a link between intrapsychic conflict and diabetic control, the authors made a case for treating the disorder by means of psychoanalytic therapy. The studies were notable for dealing with the full complexity of the psychological dimension of Type 1 diabetes in children. They also represent an early attempt to apply scientific methodology to psychoanalysis. For these reasons, the studies had a significant influence on the model this thesis aims to present and test (and which will be discussed at the end of the chapter).

The third section presents a contemporary psychodynamic perspective for Type 1 diabetes and explores the theoretical foundations of this model, namely attachment theory, mentalizing and their role in the regulation of stress. The current

state of research on attachment and Type 1 diabetes is summarized. Finally, extant psychoanalytic research is reviewed and critically discussed.

To conclude, the aim of this chapter is to provide an overview of the key works that have analyzed T1D from a psychodynamic perspective. To review the broader body of knowledge, i.e. the multitude of conceptualizations in the psychodynamic corpus and how they might relate to diabetes, would be a task which goes well beyond the goal of this chapter. Therefore, the following section concerns itself only with those works that have specifically elaborated the theoretical and/or clinical relationship between T1D and psychoanalysis.

## **Methodology of the Review**

A systematic literature review was performed in December 2015 and updated until January 2018.

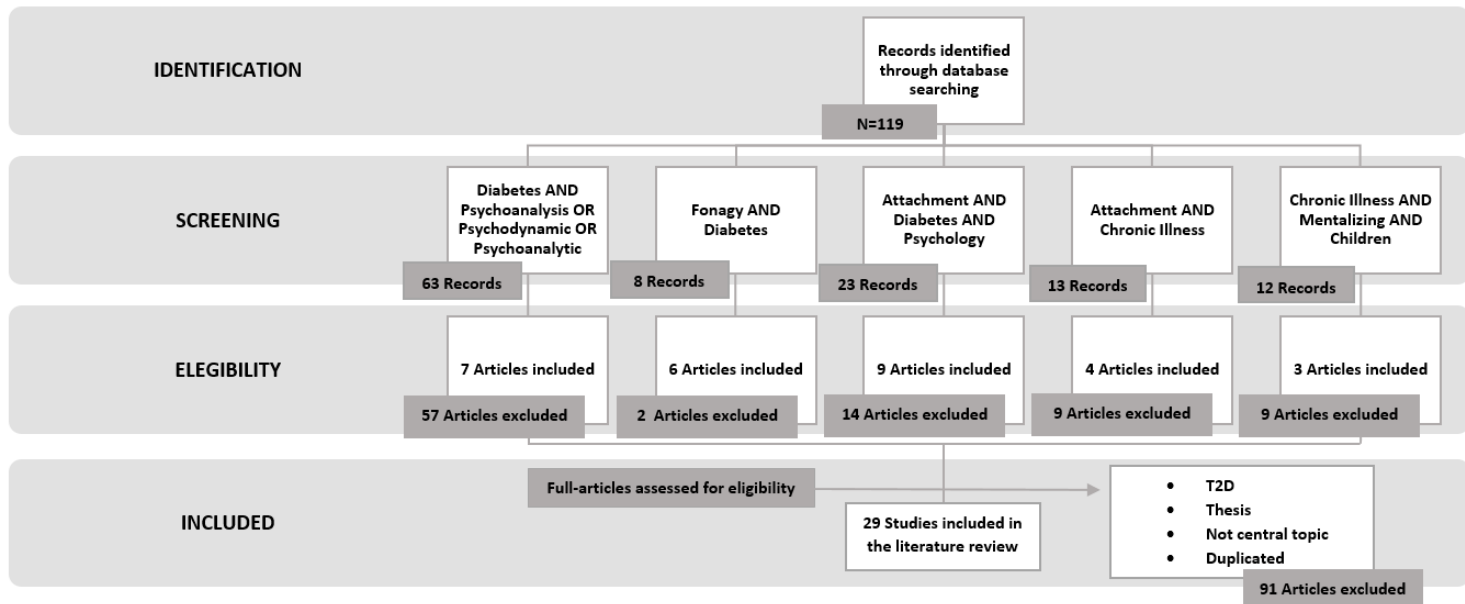
The search engines used were: Annual Reviews; APPI Journals; ASSIA Applied Social Sciences Index and Abstracts; British Education Index (EBSCO); CAIRSS for Music; Campbell Collaboration; CINAHL Plus; Cochrane Library; CogNet (MIT Press); COPAC; Dawsonera; EMBASE; EMBASE Classic; ERIC (EBSCO); ERIC (ProQuest); Health and Psychological Instruments (HAPI); HighWire Press; IBSS: International Bibliography of the Social Sciences (ProQuest); IngentaConnect; JISC Journal Archives; Journals@OVID; JSTOR; MEDLINE (Ovid version); Nature Journals; PEP (Psychoanalytic Electronic Publishing); PILOTS: Published International Literature On Traumatic Stress; ProQuest Central; ProQuest Psychology Journals; ProQuest Social Science Journals; PsycARTICLES;

PsycBOOKS; PsycCRITIQUES; PsycEXTRA; PsycINFO; PsycTESTS; Pubget; PubMed; Science Citation Index Expanded; ScienceDirect (Elsevier); SCOPUS; University of London Research Library Services; Web of Science Core Collection; and Wiley Online Library.

Using “Explore”, the advanced online search engine of University College London’s library, the following keywords were entered (title containing): (1) Diabetes AND Psychoanalysis, which provided 63 results; (2) Attachment AND Diabetes AND Psychology, which provided 23 results; (3) Attachment AND Chronic Illness, which provided 13 results; and (4) Chronic Illness AND Mentalizing AND Children, which provided 12 results.

The inclusion criteria were articles or books regarding: (1) Type 1 diabetes and psychoanalysis; (2) Type 1 diabetes and attachment; (3) Chronic illness and attachment; (4) Chronic illness and mentalizing; and (5) Published in English. The exclusion criteria were: (1) Articles about Type 2 diabetes only (T2D); (2) Dissertations; and (3) Articles in which the main concepts under review were not part of the central topic of this thesis (such as diabetes beliefs, identity, social representations, to name a few). The inclusion and exclusion criteria were applied and abstracts were assessed and included if they were in agreement with the aim of this literature review. Following this, 28 references drawn from the systematic search, were retained for inclusion in the present literature review. Concurrently, a manual search of collected papers and chapters was performed (See Figure 2.1).

**Figure 2.1: Literature Review Process**



\* Classic articles were added in order to clarify key concepts.

\* In each category, some of the most important works cited in the reviewed articles were added.

## 2.1 Traditional Psychoanalytic Approaches to T1D

In this section, a review of the main concepts in the literature focusing on diabetes from a psychodynamic perspective, will be presented. These are divided into two sub-sections: the first, “from diabetes to psyche”, examines the impact of diabetes on an individual’s life; the second, “from psyche to diabetes”, looks at conceptualizations of how specific aspects of the psychological dimension of T1D may affect the way in which patients manage the illness, including how they control their metabolism and adhere or fail to adhere to the treatment.

### 2.1.1 From Diabetes to Psyche: The Impact of Diabetes on Psychic Reality

The onset of T1D is widely understood to be a traumatic experience for both children and caregivers (D'Alberton, Nardi and Zucchini, 2012). The sudden and life-threatening quality of the emergence of the illness, together with the recognition that a key aspect of body functioning has failed and cannot be repaired, puts the child-caregiver dyad under extreme emotional pressure which challenges and often exceeds its ability to cope. This is in line with Freud's definition of trauma as "any excitations from outside which are powerful enough to break through the protective shield" (Freud, 1920, p.27)

Consistent with this notion, traditional psychoanalytic approaches emphasize the traumatic nature of diabetes and the need for both the individual and their caregivers to regulate associated feelings and thoughts. For instance, D'Alberton and colleagues (2012) argue that after T1D onset, the mother's capacity to accept her child's projections, termed *reverie* by Bion (1962), is affected in three ways: first, by the highly distressing realization that her child's life is threatened; second, by the conscious or unconscious guilt of not being able to protect her child from illness, with a concomitant "narcissistic wound"; and third, because her mental space is occupied by her own intense emotional reactions, thus reducing her capacity to contain the death feelings her child is projecting into her.

The fact that both mother and children are dealing with a traumatic experience aroused by the same event is a significant challenge in this respect. In childhood, the child's mental apparatus cannot yet deal with the quantity and intensity of this



negative affect, therefore the mother must act as a filter for the experience and “metabolize” the affects on her child’s behalf. Through this process, known in the psychodynamic literature as *reverie* (Bion, 1962), raw, unbearable affects, or “beta elements”, which the child expels into the world via the mechanism of “projective identification”, are taken in by the mother who, through a process Bion called “alpha function”, metabolizes and creates meaning from these sensory events which is then fed back to the child as more tolerable psychic objects (“alpha elements”). In this way, the mother acts as a container for experiences that are too difficult for the child to bear by himself.

A similar challenge is placed on the body-self relationship by the increased focus on somatic events and processes. The collection and testing of blood several times per day so that data can be interpreted, and decisions made about treatment interventions, places the body in the position of a “silent presence” which must be constantly acknowledged. This process necessarily requires the psyche to re-represent the body in order to achieve a coherent image of it. D’Alborton and colleagues (2012) describe this as an interruption in the continuity of bodily experiences.

This reasoning is in line with Anna Freud’s thoughts regarding physical illnesses more generally in children (1952). She argued that disease brings about changes to a child’s libidinal economy, transforming object-cathexes into body-cathexes and initiating a process of drive regression. Previous stages of psychosexual development are reawakened as the child’s body becomes reliant again on the physical presence of the caregiver for its survival.

Viederman and Hymowitz (1988) also conceive of the onset of diabetes as a trigger for the repetition of earlier developmental phases, specifically the anal stage, in which the mastery of bodily control is negotiated within the dyad. The authors suggest that the success of the treatment of diabetes depends upon how well the child has coped with this transition. They reviewed four clinical cases, examining each patient's past relationship with their mother, in terms of bodily control (e.g., intrusive), and how successful they were at dealing with diabetes in the present (e.g., good or poor control). The first patient, who had showed no signs of significant anal-phase conflict, demonstrated good control of his illness, was able to accept and depend upon his doctor's recommendations and had taken a degree of personal responsibility for his treatment. He showed good sensitivity to symptoms of hyper and hypoglycaemia and, overall, appeared comfortable in his own body.

By contrast, the second patient had a clearly conflictual relationship with an intrusive and dominating mother. Her diabetes was poorly controlled, and she showed very little autonomy in her treatment. This behaviour changed, however, when she became pregnant, a "normative crisis" which encouraged her to re-establish bodily control and take care of her diabetes. The third patient, who also had a history of intrusive mothering, was unable to trust in others or her body in adulthood, showing high levels of hypochondria and anxiety. The fourth patient displayed a passive dependency on her family, who had assumed complete responsibility for her treatment. She regularly experienced symptoms of hypoglycaemia without mentioning them, forcing people around her to take action on her behalf, such as giving her food. Her history was marked by a distinct lack of parental support, leading the authors to suggest that her diabetic treatment fulfilled

a neurotic wish for attention and control from parental figures, which is a feature of regression to the anal phase. However, they also point to the possibility of changing these ingrained patterns, as demonstrated in the second case. They attribute this possibility to the presence in the patient's history of the capacity to trust in others (an idea which will be discussed later in this section).

The reappearance of earlier states of dependence has also been observed by Daniels, (1944); Mirsky, (1948) and Dunbar (1936). All report high levels of dependency in diabetic patients associated with a regressive process. Daniels (1943) argued that this process stemmed from the experience of an "injured ego" consequent to the onset of illness. Similarly, Mirsky (1948) suggested that the most common affective experience after the onset of diabetes is the arousal of an intense need to be cared for, or a denial of this need, together with feelings of inadequacy. These intense experiences, according to Mirsky, serve to reshape the child's personality, as compensatory mechanisms for dealing with these feelings turn into personality traits (for example, an indifference towards relationships rooted in fear, or hostility caused by an intense need to be helped). These observations echo later explanations of these processes as activations of the attachment system due to stress, which promotes proximity seeking leading to ambivalence due to the consequent loss of autonomy and control.

Another renegotiation observed in these patients involves the relationship with food, which carries a risk of developing problems focused on eating. Mirsky (1948) points out that dietary restriction can be experienced by the patient as a prohibition of infantile pleasure gratification, enhancing feelings of inadequacy. The patient may feel different from his peers, especially in regard to eating within a social

context. Indeed, eating restrictions imposed by the diabetic regime have been seen to increase the risk of eating disorders (Fairburn et al., 1991; Danoiu et al., 2010). In a brief case analysis, Franzese and colleagues (2002), present the case of a 6 year-old girl with concomitant T1D and anorexia. They argue that the control of food in her life became the perfect metaphor for her inner conflict. The girl refused to eat and showed high levels of anxiety regarding food ingestion and weight gain, leading to malnutrition and significant diabetic complications. The authors discuss how some T1D patients regard food as an enemy and something that needs to be removed from their lives. This idea is similar to that of Anna Freud (1952) regarding food restriction in chronic illness. She claimed that in childhood, food restriction can be experienced as a denial of love, in addition to generating feelings of being rejected and different from other children.

In summary, although there are only a few papers within the psychoanalytic tradition that have explicitly focused on diabetes, they agree on the notion that the onset of diabetes calls for a renegotiation of fundamental aspects of psychic life. A process that was previously the silent function of the pancreas instead becomes a function of the ego (Viederman and Hymowitz, 1988). The way the aforementioned challenges are dealt with by the individual and their caregivers is thought to significantly affect the quality of their self-care, along with other elements of illness management that allow them to live with this dysregulation. This and other psychological dimensions are reviewed in the next section.

## **2.1.2 From Psyche to Diabetes: The Psychological Dimension to Diabetes Management**

### **The Role of the Regulating Object and Self-Body Integration in Diabetes Management**

The regulatory and controlling nature of diabetic treatment has often been understood using object relations models (Fonagy and Moran, 1989, 1990, 1991, 1993, 1994; Viederman and Hymowitz, 1988; Solano, 2000; D'Alberton et al., 2012). These models are concerned with the individual's relationship with his internal objects (psychic representations of others) and the regulating role that these objects can play in the relationship between the individual and his internal and external worlds (Klein, 1920; Fairbairn, 1941; Bion, 1962; Sandler, 1976).

Two main themes emerge from this approach: the relationship with an internal 'defective object' and the lack of integration of the body and self (which would allow the 'defective object' relationship to be manifested in the body).

Difficulties in self-body integration will be further discussed in the review of Fonagy and Moran's work later in this chapter. Their conceptualization has been also used by Solano (2000) and D'Alberton et al., (2012) to help understand the self-destructive nature of treatment transgression in these patients.

Solano (2000) illustrates this with a clinical case. A 44 year-old patient was repeatedly admitted to hospital after severe hypo and hyperglycaemias. He would often neglect his diabetes treatment, showing no awareness of the bodily signals of abnormal blood glucose levels, not even the most evident ones (such as confusion or tremors), resulting in frequent loss of consciousness. His relationship with insulin

was problematic. Sometimes, he would forget to inject, causing a hyperglycaemia. At other times, he would inject but then “forget” to eat, causing a hypoglycaemia. His general demeanour was characterized by an extreme denial of needs, not only regarding his diabetic treatment but also in his personal relationships, including with his analyst. He tended to violently withdraw from these relationships, in the same way that he “withdrew” the effects of insulin from his body.

He was unable to give an account of the emotions he felt when he broke up with his latest partner. Indeed, it was only after two years of analysis that he began to recognize emotions for the first time, describing, for example, the fear of intimacy that caused him to end the relationship. Subsequently, he was able to build a long-lasting relationship for the first time. His interaction with the analyst also improved, allowing discussions about his diabetes, his relationships and his treatment. Solano (2000) argued that in patients like this, conflict with a regulating object finds expression in an opposition to insulin, which, by displacing this conflict into the body, becomes a means of dealing with the distance-proximity of the object. In this particular patient, hyperglycaemia represented abandonment by the regulating object, while hypoglycaemia, in a more complex and paradoxical way, represented a form of opposition which appeared to allow the object a regulatory function (by injecting insulin) but, due to the highly dysfunctional way he indulged this phantasy, served merely to demonstrate the object’s uselessness. This disruption, Solano argued, played out as an action on the body, as it could not be elaborated in the mind.

D’Alberton, Nardi and Zucchini (2012) understand the body-self disintegration as an effect of the autoimmune nature of the illness. The experience of the body

rejecting and attacking itself produces a phantasy that being integrated with the body will lead to the same destruction. This body-self disintegration has been understood as a reason behind poor illness management. Viederman and Hymowitz argue that “a critical issue hinges on whether the individual experiences his body as an integral part of himself under his control or as an object difficult to control and an adversary” (Viederman and Hymowitz, 1988, p.39). The risk is that diabetes remains an external object. If that happens, they argue, treatment outcomes will always be poor (Debray, 2003, cited in D'Alborton et al., 2012).

A case presented by D'Alborton et al., (2012) illustrates this latter point. A 4 year-old child arrived at their clinic with his parents. The father complained that diabetes had “taken over his son, who was not the child he used to be”. Each time they tried to talk to him, the child would kick the objects around him, causing damage. The parents were so distressed that they were not able to tolerate or contain the child's anxiety. The authors claimed that this was analogous to what was occurring in the child's object relationships. As no object was available to contain his anxiety, he would damage his body by neglecting treatment as a way of expressing his internal conflict. Anna Freud (1952) similarly described how physical illness could cause children to displace their internal conflict onto the body. She noted that children who have experienced deprivation in maternal caregiving would express a bodily conflict in which the child becomes a proxy for the anxious, overprotective mother (as a compensation for the lack of care) and the body represents the misbehaving child. Although Anna Freud makes no mention of object relationships, one can assume she is giving an account of this phenomenon, involving a defective regulating object and the bodily expression of conflict with that object.

From a different perspective, Daniels (1944) presents eight cases of patients who, in his view, elaborated their psychic conflict through their diabetic symptomatology. The cases concerned patients who had experienced recurrent “insulin shocks” (severe hypoglycaemia) that were difficult to explain from a purely medical viewpoint. Some of these patients were so sensitive to insulin action that a hypoglycaemic state would occur almost immediately; in others, symptoms of insulin shock accompanied normal Blood Glucose (BG) levels, a phenomenon the author describes as a “pseudo shock”. In Freudian terms, the hypoglycaemia of the first group of patients was experienced as a “neurosis anxiety”, while the pseudo shocks of the second group constituted a “hysterical conversion”. In both sets of patients, the experience of insulin shock had the cathartic effect of discharging repressed emotional tension, producing a state of openness in which psychotherapy could occur. A decline in repression over time allowed the patients to develop new defensive strategies which, according to Daniels (1944), were more adaptive to illness treatment. This brings us to the issue of defence mechanisms.

### **The Role of Defence Mechanisms in Diabetes Management**

From a psychodynamic perspective, patients who experience difficulties in their diabetes management are commonly described as relying primarily on defence mechanisms that are incompatible with the maintenance of proper treatment. It is understood that these mechanisms are intended to defend the individual against ideas relating to death. It is not surprising that physical illness should awaken such ideas and the defences against them. The problem arises when the defence against the idea of annihilation brings the individual closer to death, as is the case here.



The first and most common defence mechanism observed in these patients is denial, either of the illness itself or of one of its aspects: its impact on the body, its chronicity, the necessity of being cared for, or its acute physical effects, such as hyper or hypoglycaemia. In the case presented above by Solano (2000), denial of these symptoms was one of the main issues underlying treatment non-compliance. The patient in question had stopped injecting himself or would “forget” to eat after injections. When, during therapy, he showed clear signs of hypoglycaemia (confusion or agitation) he would refuse to acknowledge them, even if the symptoms were pointed out to him.

Denial of this nature can be understood as the disavowal, repudiation or distortion of a reality that produces anxiety in the subject (Freud, 1925; Kernberg, 1994). In the case described by Solano, the effect was highly pathological, going beyond the mere distortion of the emotional meaning of an event (as defences are described by Freud in 1894, 1920 and 1926). In Solano’s patient, reality itself is disavowed, thereby blocking even the possibility of taking appropriate action to ensure survival, which echoes the idea that denial (negation) “belongs to the instinct of destruction” (Freud, 1925, p.239).

Along with denial, splitting is mentioned as an active mechanism in a patient with anorexia and diabetes described by Franzese et al (2002). As with Solano’s patient, this individual was not able to recognize her acute diabetic symptoms, which included recurrent hypoglycaemia, or the more general health problems caused by her anorexia (such as malnutrition). The presence of splitting, while not elaborated upon by the authors, can be seen in the way the patient directed all her anxiety towards her weight and food issues. All the negative aspects of her physical and

emotional situation centred on these themes. Anorexia in this patient started 6 months after the onset of diabetes: from then on, she presented with both recurrent hypoglycaemia and constant weight loss.

The authors report that the patient's mother suffered from major depression and a highly dysfunctional relationship with her husband. It is therefore plausible to think she had a low capacity for "containing" the child's anxiety regarding diabetes by offering a "mental space" for these affects, as described in the above section on the *reverie* process. In such circumstances, the emergence of defence mechanisms can be understood as a means by which the child was able to deal with the anxiety herself.

Other cases presented evidence of the mechanism of "displacement", linked to the fear of specific aspects of the illness, which have become charged with unconscious meaning. In this situation, the subject would avoid certain elements of treatment because they are associated with unconscious fear. In other words, some patients neglect treatment as a way of avoiding a feared aspect of diabetic management (for example, injections) or a specific consequence (for example, the fear of hypoglycaemia, but not hyperglycaemia). These mechanisms can be understood to involve a displacement insofar as the manifest anxiety represents an unconscious fear relating to intrapsychic conflict (for example, a fear of being penetrated expressed as a fear of needles).

As an example, D'Alberton et al (2012) describe the case of an 11 year-old patient who displayed an intense fear of hypoglycaemia, but not of other aspects of her illness or treatment. She fantasised about dying in a hypoglycaemic crisis and would eat more than her recommended portions of food in order to prevent this. She

also became highly distressed whenever she felt her heart beating strongly, a bodily experience very similar to that of hypoglycaemia. These panic attacks started soon after the onset of the illness. The authors attribute the patient's fear to the distress of her first experience of diabetic symptoms. They claim that such powerful affective events are so difficult to process that in certain cases, a patient's generalized anxiety becomes focused instead on a single aspect of the disease.

These displaced fears are similar to the concept of "irrational anxieties" (Fonagy and Moran, 1994; discussed in more detail in the next section). The authors describe a group of patients in their brittle diabetes sample who neglected their treatment because certain aspects of their diabetic regime had acquired an unconscious signification that the patient wished to avoid. For example, after exploration of the intrapsychic conflict of an 11-year-old patient, they concluded that the patient's phobic reaction to injections was rooted in terrifying infantile fantasies about intercourse penetration.

Defence mechanisms are a constitutive element of an individual's psyche and personality and some are more adaptive than others. When defence mechanisms lead to an unhealthy pattern of behavior, as in the cases mentioned above, there is a necessity to encourage more flexibility in order to protect the individual's physical integrity. In all the cases described in this section, defence mechanisms changed within the psychotherapeutic process. One way of interpreting this, is to consider the effect of the relationship between patient and therapist. If one accepts that defence mechanisms come into play when the psyche is unable to contain the affects of a traumatising experience, then the provision by the analyst of an "auxiliary mind" can

be seen as an effective way of expanding mental space and making additional psychic functioning available to cope with the fear and distress caused by T1D onset.

### **The Role of Therapeutic Relationships in the Management of Diabetes**

In all the cases reviewed, the authors reported improvements in their patients, especially in their diabetes control. Fonagy and Moran (1987 and 1990; discussed in detail in the next section) claim that the mechanism of change may have been the analyst's interpretation of the intrapsychic conflict and the patient's emotional response to this insight. They make no mention in these papers of specific aspects of the therapeutic relationship which might have brought about the change. However, in 1994, when discussing the case of "Emma", they state that an improvement in metabolic balance could be attributed to the patient's use of the analyst's capacity to think, feel and experience. Specifically, they point to the role of the interpretation of transference in enriching the patient's mental world by allowing the patient to include the analyst's mind in her own mind (which foreshadows the current mentalizing view of transference).

Solano (2000) gives further recognition to the therapeutic relationship as a mechanism of change. In his case study, he argues that analysis provided the patient with "a new experience of mutual regulation" (p. 302). Within the therapeutic relationship the patient was able to experience his destructive impulses in a way that was contained by the analyst. The fact that the analyst showed himself to be vulnerable, but in a controlled way, helped the patient realize that his affects had an effect on others, and this changed his entire perception of interpersonal relations. For example, he had a previous tendency to break up romantic relationships

abruptly, without acknowledging any feelings, but after two years of analysis he was able to enter into a long-lasting relationship which, when it ended, did so because he felt “scared” of being dependent on his partner’s love. Solano hypothesizes that this style of object relationship is rooted in a specific pattern of relationship with the primary caregiver, characterized by abrupt alternation between idealization and distancing. He suggests that analysis modified the patient’s internal and external relationships, and that these new relational patterns allowed for a better approach to diabetic regulation.

Viederman and Hymowitz (1988) also attribute positive change in illness management to the therapeutic relationship. They claim that the regressed state of crisis that diabetes onset brings about, allows the individual to re-experience the caregiving relationship and develop new identifications with regulating objects. As mentioned above, within the group of patients exhibiting anal-phase conflicts, a number were able to achieve good diabetic control after therapy. The authors argue that these patients differed in that they had past experiences of being able to trust in others and were therefore able to trust and bond with the medical team, with favourable results. The authors also highlight the importance of a supportive and nurturing medical environment in bringing this change about.

As can be seen in all the cases mentioned, improvements in the way patients managed their illness happened within a meaningful relationship with a caregiving other. Critically, these relationships became “spaces” in which conversations about mental states could take place. Conceptualizations about change, however, differ depending on the author’s perspective. For example, the work of Fonagy and Moran makes no explicit mention of the importance of the therapeutic relationship: their

terminology is instead clearly rooted in models that see psychic processes in a more individualistic way, using language like “intrapsychic conflict” and “insight” when referring to therapeutic change. However, in subsequent studies they begin to consider aspects of the analytic relationship, such as transference and the use of the other’s mind for enhancing the thinking process. By contrast, Solano (2000) and Viederman and Hymowitz (1988) give clear acknowledgment not only to the power of the relationship but also to specific characteristics of the “real object”: for example, the nurturing quality of the medical team is just as important as the individual’s capacity to trust.

Taking the above into account, it could be argued that the caregiving relationship in which the individual finds himself is key to his diabetes management. In childhood, this issue may be even more critical. The child’s relationship with his caregiver evolves during early life and the true characteristics of this relationship need to be elucidated in order to understand this phenomenon in a comprehensive way. However, from a classic psychodynamic model, there is a lack of a proper consideration of these fundamental aspects of the child-caregiver relationship. This issue brings us to a discussion of the limitations of the reviewed studies.

### **2.1.3 Discussion and Conclusions**

Studies of T1D from a classical psychodynamic/psychoanalytic perspective undoubtedly enrich our understanding of the psychological phenomena at play in the

disorder and its management. However, they present important limitations from both a methodological and theoretical standpoint.

Methodologically speaking, the first limitation concerns their subjective approach. In all of the studies reviewed, the data analysed consisted of observations made by the analyst within a therapeutic relationship. This may introduce a considerable bias, given the impossibility of separating the analyst's subjectivity from the phenomena observed. A similar bias can be seen in the use of the psychoanalytic model itself. By searching for evidence of psychoanalytic concepts within the patients' material, instead of trying to describe emergent phenomena, the stance of the authors was far from neutral. The extent to which objectivity is possible in psychoanalytic studies, and in psychological research more generally, is a matter of significant debate in the field of philosophy of science (Popper, 1957; Grünbaum, 1984). It is not the goal of this thesis to go further into this controversy. However, it is important to note that extra-clinical research may limit observer bias, and thus may be able to provide a more rigorous test of psychoanalytic assumptions, as will be discussed in the next section.

A second methodological limitation of the studies reviewed is their lack of systematicity. The researchers do not follow a specific method or cite previous evidence to support their findings. Nor do they clearly describe the method or process they followed in arriving at their conclusions, which would allow for greater transparency and replication. This lack of systematicity is also sometimes reflected in the language used to describe concepts and findings, which is often dense and metaphorical. This prevents the work from being understood by scholars from outside the field of psychoanalysis or integrated with other fields of knowledge. The

methodological weaknesses discussed above also reflect a notorious disconnect between psychoanalysis and other disciplines addressing mental health issues, producing an approach that we could call “localism”. Theoretical constructs are described in the context of a clinical setting which has been shown to be appropriate only for certain psychological problems and patient groups (Fonagy and Target, 1998) as well as keeping knowledge “in the family”, this has the potential to lead to a significant waste of resources.

Regarding the theoretical limitations of the works reviewed, it is important to point out the overemphasis in these studies on the patient’s past experiences, at the expense of their current social environment. This is especially important in children whose relationship with their main caregiver is evolving in support of the child’s mental and physical needs. Rather than studying actual interactions between child and caregiver, the authors reviewed in this section tend to concern themselves with how such relationships are represented in the child’s internal world (Fonagy and Moran, 1989, 1991, 1993, 1994; Solano, 2000, D’Alberton et al., 2012) or how intrapsychic conflict derived from psychosexual drives relating to the mother-child relationship in infancy can be resolved through the therapeutic relationship (Viederman and Hymowitz, 1988).

The stance taken by this thesis is that the mother-child relationship, as it plays out in observable attitudes and behaviours, constitutes the “habitat” of the child’s mental life. Within that relationship, the child’s mind emerges and is sustained. The child’s mind and mental health are therefore part of the same world. I offer a metaphor: while the human body needs around 40 weeks of gestation inside the mother’s body, the human mind seems to need a much longer gestational period



within the mother's mind. It can be argued that the gestational period of the mind extends at least throughout childhood. In order to develop fully, the child needs a significant caregiver who is able, on its behalf, to perform mental tasks that its rudimentary mind is not yet ready to perform. This is not to deny the existence and role of internal conflicts and fantasies but to look at their interaction with current ongoing conflicts and relationships.

One should bear in mind that diabetes is experienced first and foremost within the mother-child relationship. It is my fundamental belief that studying the psychological dimension of T1D in children cannot be separated from an analysis of the mother-child relationship in which that psyche develops. Following the above metaphor, the artificial separation of the two would be like treating a physical fetal illness by removing the foetus from the mother's body.

Early psychoanalytic theory conceived a similar idea:

*So far as health, hygiene and the nursing care are concerned, the mother's ownership of the child's body extends from earliest infancy, when the mother-child unity is an important factor in the libido economy of both, through all the phases of childhood into adolescence. Anna Freud 1952, pp. 79.*

Here, Anna Freud appears to be suggesting that the mental space between mother and child plays a part in creating this shared libidinal environment – and by extension a shared mind - that goes beyond the years of infancy.

I think that this fact is particularly evident in children with diabetes, where the illness forces the mother-child dyad to comply jointly with the daily tasks required for

the child's physical survival. The dyad's mental dimension remains threatened by this survival need, arousing basic anxieties in both members and impairing the natural flow of shared experience needed for the child's mind to fully emerge. More traditional psychodynamic approaches on diabetes have overlooked the intersubjective process in which the child's mind develops. In contrast, more contemporary psychodynamic perspectives are enlightened by an acknowledgement of the latter intersubjective process. In this context, the work of Fonagy and Moran (1987-1994) has played an important role in the study of Type 1 diabetes.

## **2.2 Fonagy and Moran on Type 1 Diabetes**

The next section presents a review of the studies developed by Peter Fonagy and George Moran about their psychoanalytic work with children with so-called "brittle" diabetes (Type 1 diabetes in very poor control). These are by far the most comprehensive papers addressing the psychic dimension of Type 1 diabetes in childhood from a psychoanalytic perspective. They also present a novel method, based on psychoanalytic process studies performed at the Anna Freud Centre in the United Kingdom, using a single case design with a time-series analysis method, and a control-case study.

### **2.2.1 The Studies**

The studies summarized below concern the psychoanalytic treatment of children and adolescents with so-called “brittle” diabetes and are reported in five different papers and chapters (Moran and Fonagy, 1987; Fonagy and Moran, 1990; Moran, Fonagy, Kurtz, Bolton and Brook, 1991; Fonagy and Moran, 1993; Fonagy and Moran, 1994). Brittle diabetes is a term used for patients with serious difficulties in regulating their diabetes, with recurrent hypoglycaemia, ketoacidosis and hospital admissions, and who are therefore at a high risk of health complications (Tattersal, 1985)

Each of the Fonagy and Moran studies reviewed here begins with a discussion of the causes of brittle diabetes in which the authors state that the effect of emotional factors in diabetic control are undeniable and should be considered. Across the studies, they propose two psychosocial factors that could trigger the imbalance that causes brittle diabetes. First, they argue that stress and anxiety are related to metabolic disturbance (as is now widely recognized - see discussion in Chapter 1). In line with what has already been discussed in this thesis, Fonagy and Moran argue that the experience of stress affects the metabolism via stress-related hormones (such as cortisol, adrenaline, catecholamine), which affect the absorption of insulin and diminish its regulating function (Barglow, Berndt, Burns and Hatcher, 1986). In turn, patients with poor metabolic control are more sensitive to stress because recurrent imbalances weaken the homeostatic capacity of the neuroendocrine system: more stress hormones are already circulating through the

blood leading to an exaggerated stress response to relatively mild stressful events (Gilbert, Johnson, Silverstein and Malone, 1989).

A second psychological causation of brittle diabetes proposed by the authors, are the treatment transgressions that lead to metabolic imbalance. They argue, based on the cases analysed, that such transgressions are rooted in psychosocial problems (Fonagy, Moran and Higgitt 1989). I will discuss this idea in more detail further on in the chapter.

Having presented the commonalities across Fonagy and Moran's papers and chapters, I will next review the specific cases they analysed. The first study was a single case report (Moran and Fonagy, 1987) testing the hypothesis that in psychoanalytic psychotherapy, as a result of the psychoanalytic process, symptomatic improvement would occur in chronological association with increasing insight, using the treatment of a patient with brittle diabetes as an opportunity to observe how the neurotic conflict resolution operates. First of all, the authors offered a psychoanalytic model for the understanding of brittle diabetes, as outlined above, based on two assumptions: 1) psychological variables would have a causal relationship with metabolic fluctuations in diabetes; and, 2) these fluctuations are based on conscious or unconscious acts related to treatment transgressions.

Through a systematic non-experimental single-case design methodology, data from a 3½ year, five-times-weekly psychoanalysis of a diabetic teenager (Sally) was analysed. Sally's psychoanalysis started when she was 13 years old (5 years after her diabetes onset). Her difficulties included a tangled relationship with her mother, gender dissatisfaction and fear of attending school, which appeared immediately after the onset of diabetes. Moreover, she presented recurrent hypo

and hyperglycaemias and between 2-5 admissions to hospital per year (symptoms that disappeared or significantly diminished after the analytic process was complete). Sally's analysis was examined through an in-depth consideration of associations between variations in diabetic control on the one hand, and variations in the themes of the psychoanalysis on the other, using a time-series analysis method (Box and Jenkins, 1976) which allowed the authors to establish causal inferences by considering statistical descriptions of fluctuations, cycles and trends that occurred during both processes.

Diabetic control was measured using two daily urine tests. Psychoanalytic content was analysed on the basis of daily reports made by the analyst after each session, which resulted in weekly reports. A clinical paper condensing the total of 148 weekly reports was analysed in order to extract the main analytic themes. Once the themes were established, an examination of each weekly report was undertaken, which focused on the presence/absence of the theme in the session. This was carried out by the analyst and by two independent rating colleagues (both child psychoanalysts) who showed high inter-rater reliability.

Of the 5 main themes that were extracted, the one most significantly associated with variations in diabetic control, was: "Sally's feeling unloved by her father and angry with him". This implied that during periods in which this theme was present in the analysis, the patient's blood sugar levels were lower (thus, metabolic control was better). According to the authors, these results showed how working to resolve psychic conflict could predict an improvement of diabetic control in the short and long term (there was a 4-year follow-up). The authors claimed that these results also supported the formulation of the psychosomatic aetiology of brittle diabetes.

In a second study (Fonagy and Moran, 1991), the effectiveness of an intervention combining psychoanalytic psychotherapy and medical management in an inpatient context with patients with brittle diabetes was tested. The aim of the intervention was to help children understand the conflict underlying their emotional distress and regimen transgressions. They expected psychoanalytic treatment would enhance metabolic control through a reduction of distress and improve diabetes treatment adherence through an understanding of the conflict underlying regimen transgressions.

A total of 11 children received the entire treatment, which consisted of 45-minute sessions, 3-5 times weekly, for 15 weeks on average. The treatment was carried out by two child analysts with a similar background in regard to training and experience.

The control group was formed of 11 children, who instead received only the usual hospital procedure for metabolic stabilisation without any psychotherapy. Psychological assessments were carried out before the treatment started for the 22 children. A total of 50% of the children in both groups showed significant psychological disturbance and the majority of them presented with mixed emotional states. Also, one girl in each group presented with an eating disorder. Further to this, each child was interviewed about their thoughts and emotions regarding diabetes. These assessments were only performed at the beginning of the study and not after the treatment.

Diabetic control was assessed considering two measures of glycaemic control (M-value and HbA1c). Dynamic hypotheses were established for each patient about their psychological disturbance, considering both the patients' explicit

discourse about their diabetes (for example, a girl of 12 who believed that there was no point to having treatment because, she said “diabetics should die” and she would have health complications anyway) and consideration of intrapsychic conflicts (for example, the same girl was unconsciously identified with her dead mother; the conscious hopelessness regarding her treatment was linked to an unconscious hopelessness regarding her father’s interest in her).

The main goal of the treatment was to explore how the following issues were expressed through the metabolic imbalance: 1) repudiated sexual or aggressive desires; 2) diabetes as a vehicle for guilt; 3) diabetic imbalance as a way to avoid other difficult conflicts; 4) diabetic imbalance as a way to express unconscious anxieties about physical damage; 5) diabetic imbalance as a path by which separation and dependence issues can be expressed; and, 6) diabetic imbalance as a way to divert the child’s attention from other painful internal or external conflicts. The main focus was to foster insight and to enhance the child’s capacity to deal with the unconscious thoughts and emotions underlying the necessity to actualise psychic conflict through treatment transgressions.

After treatment, blood glucose levels were found to be substantially lower than those taken at the time of admission within the treated group. These reductions were maintained 1 year after the end of treatment, and the children stopped having episodes of hypo- and hyperglycaemia. Children in the comparison group did not improve their metabolic control nor the frequency of hospital admissions for metabolic imbalance. The authors concluded that these results implied that psychosocial irregularities were not secondary to the endocrinological problems, but rather primary and reversible. Although the authors clarify that concluding an exact

mechanism of change cannot be drawn from these results (because of its methodology), they do suggest that the exploration of the functions that the illness mismanagement was fulfilling, both at a conscious and unconscious level, may have been a key aspect in achieving a good control.

Besides these two studies, Moran and Fonagy presented extracts of similar cases in three other papers (Fonagy and Moran, 1990; Fonagy and Moran, 1993; Fonagy and Moran, 1994). In both the 1990 and 1993 paper, they presented the case of three diabetic adolescents with growth retardation (related to metabolic problems) whose height data indicated that medical procedures had been unhelpful over the previous 2 years. Their “height velocity standard” (HVS) was measured before, during and after the psychoanalytic treatment and their HVS improved significantly during and after psychoanalysis, as well as their metabolic control.

In the 1994 paper, Fonagy and Moran presented an extract from the case of “Emma”, an adolescent with an important diabetic imbalance, recurrent ketoacidosis and frequent hospital admissions. She tended to omit insulin to lose weight and she had regular episodes of drug abuse and binge eating. Both parents were psychotic. Her self-harming behaviour was interpreted as an expression of repudiated parts of herself. It was a way of dealing with dangerous and chaotic feelings and ideas that threatened the integrity of her mental world, so they were located in the body to maintain them separately from her mind. Because she experienced her body as something separate, she did not feel that such attacks to the body were attacks on herself. The authors highlight that the latter movement entails an inhibition of Emma’s mental functioning, which was precisely the process which was restored within the patient-analyst relationship.



Fonagy and Moran offer an interpretation regarding the causes of metabolic control improvement in Emma that can be understood as a precursor of the shift to a mentalizing approach (discussed in the next section), and therefore constitutes an essential idea for the present thesis. They attributed the therapeutic change that occurred to the use of the analyst's capacity to think, feel and experience, and to the work of interpreting the transference which allowed Emma to incorporate the analyst's mental process into her own mental world and to relocate the psychic dynamics being held in the body into a representational dimension. With this process, she was developing the ability to "exercise her mental capacity for conceiving human actions in terms of desires, to represent ideas as ideas rather than as concrete aspects of her bodily world. This (...) is the technique most relevant to severely disturbed diabetic patients" (1994, p.80).

To return to the common aspects found in Fonagy and Moran's studies, as explained earlier, the idea of two presumed pathways of psychological causation of diabetic imbalance is discussed in their work. The first involves a weakened neuroendocrine system due to frequent metabolic imbalance and the consequent hyper response to stressful input (discussed above). The second involves the conscious or unconscious acts of transgression of the prescribed treatment regimen. The latter is further elaborated in the most recent works (1993 and 1994) in which the authors offer a complete psychoanalytic interpretation of the self-injurious nature of treatment transgressions. They state that the self-destructiveness present in all the patients analysed, can be explained by the presence of three patterns of behaviour.

The first pattern interpreted by the authors was *the diabetic imbalance as a distance-regulating function*: in some patients the imbalance can be understood as a way of dealing with distance-proximity with their object, whereby psychic experiences that have remained beyond the reach of representation are actualised in the body. Some specific physical experiences linked with diabetic dysregulation are lived as “psychic equivalents” (Fonagy and Moran, 1993, p.171) of the relationship with the object. For example, the experience of being abandoned in hypoglycaemia and rescued in hyperglycaemia. The patient struggles to build a mental space between the self and the object through the metabolic imbalance, and because the object is not conceivable on a mental level, the only way to obtain proximity with, or distance from, the object is by acting it out in the body. These patients experience their bodies as separate from themselves and it is because of this representational separation, that they are able to tolerate such a large amount of pain. In these cases, the patient has eliminated the psychological function of their objects and of the representation of the self in its affective interaction with objects, because in this way, they are protected from the painful awareness of the violence and irrationality in their caregiver’s mind (Fonagy and Moran, 1991). The authors suggest that in extreme cases this developmental disturbance could lead to resistance in the child to think in his or her own or other’s mental worlds.

The second pattern relating to *acts of treatment transgression* is the unconscious use of the illness for manipulating an unpleasant aspect of the child’s reality. This involves a neurotic adaptation to anxiety and guilt. An example of this would be a child trying to unite his or her divorced parents by making them ensure his or her survival through recurrent hospital admissions. Alternatively, some diabetic

children neglect aspects of treatment because they unconsciously symbolise a threat. This has also been termed “irrational anxieties” by the authors and constitutes the third pattern of behaviour. An example of this is the phobic reactions to injections due to terrifying penetration fantasies, as in the case of the 11-years old boy briefly presented in the previous section.

### **2.2.2 Discussion**

Fonagy and Moran made an enormous contribution to the field, even though the procedures used in their studies would be very hard to replicate in present times. It could be argued that because their observations were based on psychoanalytic processes, their ‘data collection’ was extremely drawn out, expensive and realisable only by using highly trained professionals. Moreover, the ‘data’ itself may have been biased from the outset, because it came from the analyst’s observations of a relationship of which he was part of, and where their subjective processes are undeniably impactful. However, unlike the majority of psychoanalytic research (as discussed in the previous section), in the studies reviewed it is visible how the authors take charge of this potential skewing of the results by supporting analyses using systematizations such as case-control and time-series methods. Also, in their conclusions they clearly state that because of their design, cause-effect relationships cannot be attributed, and even though the methods used can be criticized, they are far more rigorous from a scientific point of view than more traditional psychoanalytic accounts. Yet, the model proposed for understanding diabetic imbalances can result

in overly broad findings, and this breadth can lead to ambiguity. For example, the interpretations of causes of treatment transgressions offered by the model are almost impossible to refute: how can someone demonstrate that a patient's treatment omission is *not* caused by an unconscious motivation?

Needless to say, the work on diabetes by Fonagy and Moran is pioneering in integrating a systematic approach to test psychoanalytic assumptions concerning diabetes and they have played a pivotal role in the development of contemporary psychodynamic models of mentalising, which will be reviewed next.

### **2.3 T1D from a Contemporary Psychodynamic Approach Rooted in Mentalizing and Attachment Theory**

*Emotional development has been found to be complex, yet capable of being investigated by scientific method (Donald Winnicott, 1988, p.39)*

Mentalizing and attachment theory are at the centre of contemporary psychodynamic attempts to address the methodological and theoretical limitations of more traditional psychoanalytic approaches, as discussed earlier in this chapter. I argue that these perspectives provide a more comprehensive way to understand Type 1 diabetes in childhood. They do so by offering a developmental approach that acknowledges the importance of the mother-child relationship as the critical interpersonal context of development, while also considering aspects of the child's subjective experience and internal world (as opposed to purely behavioural approaches common in health psychology). In the present section, contemporary

psychodynamic models will be discussed and the literature on attachment and Type 1 diabetes reviewed.

While there is currently no model for understanding Type 1 diabetes from a contemporary psychodynamic perspective, recent research into chronic physical conditions (such as functional somatic disorders) suggests that an approach which examines the relationship between attachment experiences, mentalization and stress regulation can be effective in informing treatment and prevention (Luyten, Lemma, Van Houdenhove, Target and Fonagy, 2013).

Applied to the field of T1D, such a focus would allow us to understand the illness from a developmental and person-centered standpoint, paying particular attention to the subjective experience of patients and their caregivers and its impact on interpersonal regulation. The aim of this section is to present such a model by focusing specifically on the role of attachment and mentalizing in stress regulation in Type 1 diabetes.

The starting point of the theoretical model is that the onset of diabetes, its daily management and potential complications, are an important source of conflict and stress for the child and its caregivers, as noted above. Generally speaking, stress responses are triggered by a threat to the individual's survival, initiating physiological processes designed to mobilize and reorganize the body's resources for the sake of maintaining bodily integrity. As a result, both physiological and psychological systems are activated in order to attempt to down-regulate the stress response and restore bodily allostasis (McEwen, 2007).

One important particularity of the stressful experience of T1D is that the threat largely comes from within the individual's body. It is also permanent, which means that the individual is confronted with a near-constant activation of the stress response. Chronic activation of the stress system is known to be associated with several health problems in the general population (Gunnar and Quevedo, 2007). It is likely, therefore, that stress produces specific impairments and complications in people with T1D (see Chapter 1). As was discussed in Chapter 1, the stress response in diabetes causes health complications directly, through endocrinological mechanisms involved in the regulation of stress and blood glucose levels, and indirectly, when the subjective experience of stress leads patients to neglect their treatment. These complications, in turn, may lead to further stress and a vicious circle ensues.

Crucial to the approach outlined here, is that as part of the stress response, an individual's attachment system is activated (Bowlby, 1969 and 1973; Collins & Read, 1990; Bartholomew & Horowitz, 1991; Mikulincer & Florian, 1995; Fraley & Shaver, 1998; Mikulincer & Shaver, 2007). Indeed, the attachment system should be seen as a biological system that is activated, like the stress system, in times of threat and/or distress, and plays a crucial role in attempts to down-regulate distress. Activation of the attachment system triggers a series of behaviors, including, the seeking of proximity to a caregiver (Sbarra and Hazan, 2008).

If this process proceeds successfully, the individual achieves a sense of safety and the attachment system is deactivated. However, the process can be impaired if the magnitude or persistence of the threat is such that the usual attachment strategies adopted by the individual are not enough to down-regulate the

stress response. In such cases, the stress response system remains over-activated, leading to physical and psychological disruptions which in turn produce more stress, creating a second vicious circle that also severely affects the way the individual is able to reflect or mentalize on the self (and particularly the bodily self) as well as others (Luyten and Fonagy, 2016).

The above account provides the outline for a potential model for understanding how T1D affects the subjective reality of the individual with diabetes and how stress may affect the course of T1D (See Figure 2.2). Particularly in children, any theoretical model should include a focus on the impact of these vicious cycles on primary attachment figures, individually and as a relational unit. Any theoretical model of T1D must therefore take account of the capacity of a *relational system* to deal with the stress associated with the illness. Given the role of the attachment system in the co-regulation of stress, the premises of attachment theory would appear to be ideal for understanding this phenomenon from a dyadic perspective (See Figure 2.2).

In the next section the key elements of the model will be described in further detail. For this purpose, an overview of attachment, mentalizing and their role on the regulation of stress will be presented. Next, a review of the current literature on attachment and Type 1 diabetes will be critically reviewed. This lays the groundwork for the empirical studies reported in Chapters 3 to 5.

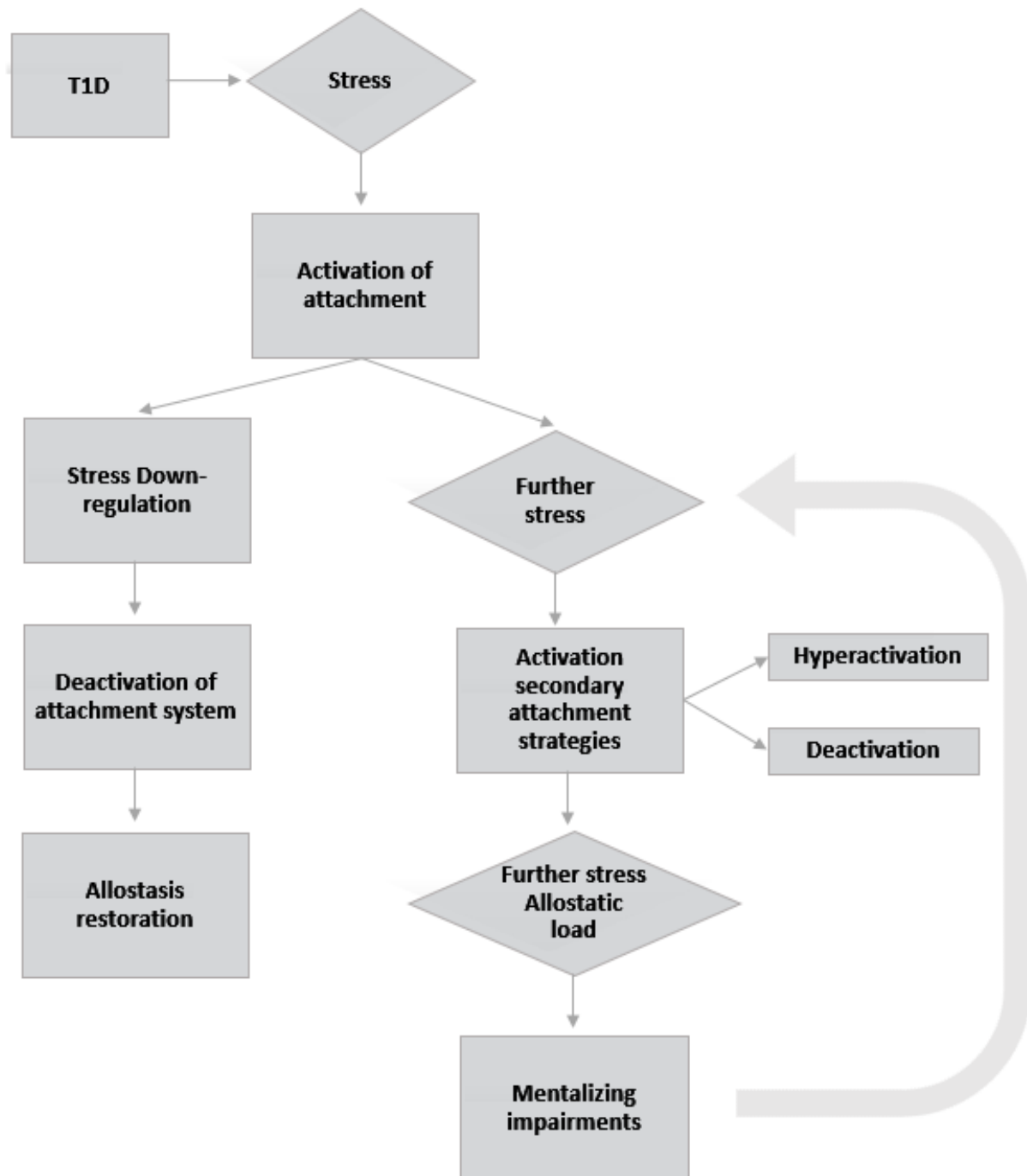
### **2.3.1 Attachment and Mentalizing: A Theoretical Framework**

Human attachment and mentalizing emerge from the interaction between at least two minds. That is to say, the bio-behavioural system for the regulation of stress that attachment constitutes develops within a caregiving relationship, characterized by repeated interactions in which the caregiver soothes the infant by interpreting their distress in terms of intentional mental states (Fonagy, Gergely, Jurist and Target, 2002)

To gain an understanding of these complex processes, it is necessary to discuss the roles of attachment and mentalizing separately; however, one could argue that mentalizing and attachment are, developmentally, steps along the same journey.



**Figure 2.2: Model Outlining**



## **Attachment Theory**

Attachment theory was first formulated by John Bowlby (Bowlby, 1969, 1973, 1980), based on his claim that close affectional bonds are a universal human need. He postulated that humans are born with a biological drive to bond and socialize and that this manifests itself in the child's earliest behaviours. One of the clues to this need is the observation that all human infants show behaviours of proximity-seeking to the caregiver (especially in times of stress) and these are matched by their caregiver's behaviours. Indeed, it is thought that attachment is a bio-behavioural mechanism whose complementary behavioural system is caregiving (George and Solomon, 2008). The attachment system is activated when the child is confronted by a threatening situation that is either external (like a natural disaster), internal (like illnesses) and/or involves separation from the caregiver (Ainsworth, Blehar, Waters and Wall, 1978).

The child's fear activates a need for attachment and the mother's fear for her threatened child activates her caregiving system (Cassidy, 2008). Therefore, it can be said that infants attach to their parents and parents bond with their children (Allen, 2013). It follows from this that humans are not born with the capacity to regulate emotions on their own. This capacity emerges from a dyadic (and actually broader relational) system in which the caregiver understands and responds to an infant's signals. The goal of the attachment system is the experience or feeling of security. In time, the infant starts to understand that being close to the caregiver can provide that feeling. Therefore, the attachment system is first and foremost a system for the

regulation of stress (Sroufe, 1996). Following repeated patterns of interaction with the caregiver, the infant internalizes an “internal working model” of how relationships work: a system of expectations regarding the self and others that allows it to interpret the behaviour of its attachment figures and take this as the norm for future relationships (Bowlby, 1979).

Combining these concepts, Mary Ainsworth developed an experimental procedure for assessing patterns of attachment in infants on which the main body of research into attachment theory was based. Indeed, Ainsworth can be considered to be the “mother” of attachment theory (Allen, 2013). This experimental procedure, called “the Strange Situation Procedure” (SSP; Ainsworth, Blehar, Waters and Wall, 1978), assesses the impact on the infant of separation from the mother, thus allowing observers to infer the infant’s level of attachment security with its main caregiver. Based on their response to the strange situation it is possible to classify infants into four categories: (a) insecure-avoidant; (b) secure; (c) insecure-ambivalent and (d) disorganized.

Secure children are able to express their distress at the experience of abandonment provoked by separation in the SSP, knowing that this will be recognized and soothed by the (trusted) caregiver. Upon return, the child’s distress is quickly soothed when in contact with the caregiver, the attachment system is no longer activated and the child is able to explore and play confidently.

Insecure-avoidant children tend not to show signs of distress following separation. This is thought to result from an over-regulation of affect, including suppression of overt signs of distress, in the interests of remaining close to the attachment figure and out of fear that an expression of emotion will lead to the

caregiver rejecting them. Upon reunion, the insecure avoidant child displays no proximity-seeking behaviours.

Insecure-ambivalent children are prone to exaggerate their expression of distress in order to gain the attention of an inconsistently responsive caregiver; their emotions, in other words, are under-regulated. In the SSP, insecure-ambivalent children show strong distress on separation and intense proximity-seeking upon reunion. However, despite the closeness with the caregiver the child remain distressed.

Finally, Mary Main and Judith Solomon (1986, 1990) found evidence for a category of so-called disorganized children, that show an inconsistent attachment strategy, presumably as the product of repeated experiences with an attachment figure that may represent themselves a source of stress, by displaying “subtle frightening, frightened or dissociative behaviours toward their infant” (Granqvist et al., 2017, p. 3). In such cases, the caregiver is unable to realize that they are frightening to the child, or to recognize the state of fear in their offspring, and their attempts at soothing will often fail. As a consequence, disorganized children suffer from chronic activation of negative emotional states (Ainsworth, 1985; Ainsworth, Blehar, Waters and Wall, 1978).

It has been shown that these attachment patterns are relatively stable across the life span, although there is also considerable evidence that life events, such as chronic distress, may lead to major changes in attachment patterns (Fraley, 2002; Fraley & Roberts, 2005). Therefore, although large-scale longitudinal studies (Main, 1997; Waters, Merrick, Albersheim, Treboux, and Crowell, 1995) have shown that attachment classifications in infancy using the Strange Situation Procedure have a

concordance of about 68-75% with those obtained in adulthood using the Adult Attachment Interview (AAI; George, Kaplan and Main, 1985), there is considerable room for changes in attachment across the life span (Sroufe, Egeland, Carlson & Collins, 2009).

Despite its obvious complexities, the intergenerational transmission of attachment is a pivotal issue in developmental research. One presumed key mechanism in the intergenerational transmission of attachment is the caregiver's capacity for mentalizing (Fonagy, Gergely, Jurist, & Target, 2002; Fonagy et al., 1995; Slade, 2005). The next section will provide an overview of this concept and relevant research.

## **Mentalizing**

Mentalizing is the capacity to understand ourselves and others in terms of intentional mental states, such as beliefs, desires, feelings, attitudes and goals. This capacity is a developmental achievement, and it is primarily rooted in the quality of early relationships (Fonagy and Allison, 2012).

Mentalizing develops within a relationship with a caregiver who is able, through *marked mirroring* and *ostensive communication*, to foster the child's understanding of mental states. This contributes to the development of the self, of attentional control systems and of affect regulation strategies (Luyten, Mayes, Target and Fonagy, 2012). With regard to the present study, it is essential to emphasize that full mentalizing is presumed to entail a capacity for "mentalized affectivity" (Jurist, 2010), an understanding of one's own feelings that goes beyond intellectual

awareness and is not limited to an inner acknowledgment and control of affective states. Rather, it involves actively experiencing and reflecting upon current affects in light of past experiences (Jurist, 2010). This also includes the capacity for embodied mentalizing, namely, the ability to acknowledge bodily signals and link them to underlying mental states (Spaans, Veselka, Luyten & Buhning, 2009).

Mentalizing also implies an awareness of the interpersonal context of our feelings and the need to be understood by others in terms of our mental states (Allen and Fonagy, 2006). As noted, this ability is modeled on early experiences with the caregiver and depends upon the caregiver's capacity to perceive the infant's intentionality. It is a psychological capacity intimately related to the representation of the self and forms part of the subject's core identity.

Although more research is needed to investigate the developmental achievement of various features of mentalizing, currently it is assumed that the capacity for mentalizing develops roughly as follows (Fonagy, Gergely, Jurist and Target, 2002):

First, at around 8- 9 months (Tomasello, 1999), infants begin to understand actions in terms of the actor's underlying intentions (Baldwin et al., 2001) and to understand themselves as teleological agents, meaning that they can impute intention, but only from what is physically apparent (Csibra and Gergely, 1998; Leslie, 1994).

By the second year, children understand that they and others are intentional agents whose actions are caused by prior states of mind, such as desires (Wellman and Phillips, 2000). They also start to understand that others have feelings and desires and they are able to demonstrate this understanding through an increasing

use of language about internal states (Repacholi & Gopnik, 1997). However, the child is not yet able to represent mental states independently of physical reality (Flavell and Miller, 1998).

At the next stage, when around four years old, children understand that behaviours in others are caused by their beliefs (Wimmer and Perner, 1983). The child is now able to perceive him or herself and others as representational agents, a milestone which revolutionizes their social world.

Finally, by the age of six the child is able to relate memories of their intentional activities within a coherent causal-temporal framework. This has been called “the temporally extended self” (Povinelli, 1995). In later life it is possible for individuals to slip back into non-mentalizing or pre-mentalizing modes of thinking. This is particularly common in certain psychopathologies such as Borderline Personality Disorder (Bateman and Fonagy, 1999, 2004, 2006).

Such rudimentary modes of mentalizing may take three forms: psychic equivalence, pretend mode and teleological mode (Target and Fonagy, 1996; Fonagy et al., 2002):

Psychic equivalence is a mode of experiencing the internal world as being equivalent to the external world, with no space for alternative perspectives. By contrast, in the pretend mode the internal experience is perceived as being disconnected from the external world, with no implications upon it. Finally, the teleological mode appears when mentalizing ceases completely. In this mode, only concrete, physical, observable cues are considered, and physical reassurance is needed in order to regulate emotions.

## Attachment Theory and Mentalizing

*“There is a vital synergy between attachment processes and the development of the child’s ability to understand interpersonal behavior in terms of mental states” (Fonagy, Gergely, Jurist and Target, 2002)*

Bowlby stated that the advantage attachment gives to our species is to have a behavioural system that allows infants to be close to the caregiver and assure their survival. However, Fonagy and colleagues (1998, 2003, 2007) have taken this argument a step further by arguing that attachment gives us the advantage of being able to move in a complex social world: attachment relationships engender our capacity for social cognition and its role as an organizer of physiological and mental regulation.

Mentalizing is acquired within an intersubjective process in which the caregiver behaves toward the infant in such a way that the latter understands he or she has ideas, feelings, wishes and beliefs. In other words, the infant becomes able to recognise his or her mental states through the caregiver’s mental world (Fonagy et al., 2002). The experience of behaviour being thought about and understood by the caregiver, in terms of intentional mental states, is thought to be at the root of the emergence of mentalizing.

Secure attachment and mentalizing develop within the same relational context. It is thought that individuals who grow up within the context of secure attachment relationships have access to more opportunities to acquire an understanding of minds (Fonagy et al., 2002). In contrast, the avoidant child learns



early on to avoid a consideration of mental states, while for resistant children their own distress hinders the development of a full capacity for mentalizing. Finally, disorganized children tend to become hyper-vigilant to the caregiver's mental states, as these are seen as posing a potential threat.

A secure caregiving environment allows a child to discover his psychological self within the social world; this in turn enables the emergence of an early mentalizing capacity (Gergely, 2001). Within this environment, the child gradually learns to understand that his or her actions have an external effect and are rooted in something that is inside him or her, i.e. internal self-states. This distinguishing of internal feelings and external situations occurs through the process of marked mirroring, as described above, and is the basis for affective regulation as it allows the child to construct second-order representations of its own feeling states. For these mirroring interactions to be effective, they have to be congruent with what the child feels but, at the same time, they must be *marked*, meaning that the caregiver provides cues to the child for understanding that this reflected emotion is a modulated version of the emotion he or she is feeling and is neither the emotion itself, nor the emotion of the caregiver (Fonagy et al., 2002).

The capacity of the caregiver to perceive the child as an intentional being is regarded as the basis for "sensitive caregiving", which for decades has been understood as the cornerstone of attachment (Fonagy et al., 2002). This ability to "mentalize" the child is also seen as key to the development within the child of the capacity to regulate his own internal states.

There is strong evidence that the caregiver's capacity to think of her child in terms of mental states (i.e., parental mentalizing of the infant) is linked with the

development of affect regulation and secure attachment in the child himself (Meins et al., 2001; Oppenheim and Koren-Karie, 2002; Slade et al., 2005). Even before the child's birth, the parent's mentalizing ability is predictive of the child's mentalization at five years (Steele et al., 1996). This evidence helps us to understand the "transmission gap" (Fonagy and Target, 2005), i.e. the mechanism by which attachment security is transmitted across generations: "The process of acquiring mentalization is so ordinary and normal that it may be more appropriate to consider secure attachment as providing an environment that is free of obstacles to its development rather than providing active and direct facilitation" (Fonagy and Allison, 2012).

From a neurobiological point of view, there is increasing evidence linking attachment and mentalizing to the same functional systems in the brain. Attachment is linked to the dopaminergic reward system, involving a number of mesocorticolimbic circuits (Luyten & Fonagy, 2015). Attachment behaviours are therefore associated with feelings of pleasure that motivate the individuals to seek out and maintain close proximity to caregivers. Significantly, the same neurobiological systems are believed to enhance sensitivity to social cues (which is linked with the capacity to mentalize (Luyten & Fonagy, 2017).

### **Attachment, Mentalizing and the Regulation of Stress**

Attachment and mentalizing act in coordination when there is a need to regulate stress. When attachment is activated, the neuroendocrine system for stress regulation (HPA and sympathetic nervous system) is activated as well, and vice

versa (Luyten & Fonagy, 2015). At the same time, neural systems involved in mentalizing come online, including the prefrontal lateral medial cortex, lateral parietal cortex, medial parietal cortex, temporal medial lobe and anterior cingulate cortex (Fonagy and Allison, 2012; Fonagy and Luyten, 2009).

Stress has been conceptualized as a perceived threat to the individual's homeostasis and as a situation that causes an increase in autonomic nervous system activity or hormone secretion (Cicchetti and Walker, 2001). Responses to stress vary widely among individuals but usually involve both biological and psychological processes. Biologically, the stress response includes the activation of specific brain circuits and neuroendocrine systems (Lopez, Akil and Watson, 1999), prompting a range of autonomic, endocrinological and immunological events.

The main endocrine system for the regulation of stress in mammals is the hypothalamic-pituitary-adrenal (HPA) axis (Vazquez, 1998). Activation of this system triggers a series of biochemical and hormonal processes designed to reestablish bodily homeostasis through the delocalization of the body's energy and resources. For example, pulmonary and heart activities increase in order to provide more glucose and oxygen to the muscles. However, if this process occurs too often, its adaptive function can be impaired (Sapolsky, Romero and Munck, 2000). Through its impact on other physiological systems, especially the immune system, the experience of continuous stress has been associated with negative health outcomes (Sapolsky, 1994).

The stress response is strongly influenced by the quality of caregiving and attachment relationships in particular (Gunnar and Cheatham, 2003, Gunnar and Quevedo, 2007; Gunnar et al., 1996). Indeed, as noted, it has been argued that

effective management of stress involves a process of co-regulation which takes place within a relationship with attachment figures (Diamond and Aspinwall, 2003; Luyten, Mayes, Fonagy and Van Houdenhove, 2009; Sbarra and Hazan, 2008).

The continuous experience of co-regulation, and the internalization of this in the form of a secure attachment strategy, has been shown to lead to an “adaptive hypoactivity” of the HPA axis in early childhood (Gunnar and Quevedo, 2007). Early experiences of a supportive social environment also fosters flexibility and resilience in the face of stressful situations (Gunnar and Quevedo, 2007). By contrast, experiences of insecure attachment – and particularly of disorganized attachment – are associated with impairment of the biological systems involved in the stress response and with negative health outcomes (Gunnar and Quevedo, 2007).

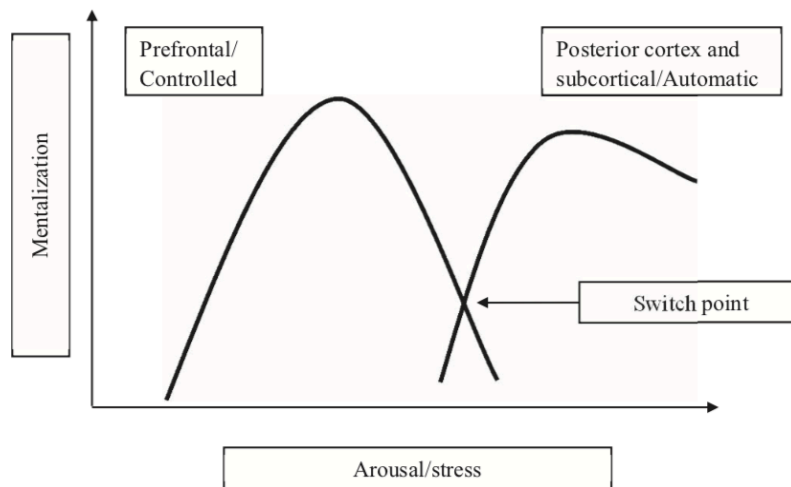
However, when confronted with a serious or constantly stressful situation even securely attached individuals increasingly have to rely on so-called secondary attachment strategies, which are characteristic of insecure attachment styles. These strategies can be divided into two categories: hyperactivation and deactivation of the attachment system (Fonagy and Luyten, 2009). Hyperactivation of attachment is typical of individuals with anxious attachment styles. It is characterized by increased efforts to obtain relief, excessive dependency on others and clinging behaviours. There is an underlying belief in such individuals that others will not be available at times of distress. Even when help is forthcoming, the individual will feel it is not enough, and will often chase others for support, albeit in a similarly rejecting manner.

By contrast, deactivation of the attachment system brings about a denial of attachment needs and a false affirmation of individual autonomy and strength in regulating stress. This strategy imposes high interpersonal, metabolic and allostatic

costs, makes loneliness and isolation more likely and is linked with ongoing vulnerabilities in terms of stress responses, especially those mediated by the HPA axis (Luyten et al, 2010).

The use of secondary attachment strategies also increases the tendency to switch to pre-mentalizing modes of thinking, as discussed in the previous section (Fonagy and Luyten, 2009; see Figure 2.3). Unable to regulate distress, the individual increasingly tends to distort his/her subjective reality and that of others. This is particularly relevant in the context of T1D as will be discussed in more detail below. Indeed, evidence has shown that the impact of stress on the prefrontal and dorsolateral cortex leads to a transitory switch from reflective processing of social information to automatic and often biased processing of information (Reyes, et al., 2015; Fonagy and Luyten, 2009).

**Figure 2.3 – Bio-behavioural switch model of the relationship between arousal/stress and controlled versus automatic mentalizing.**



(Based on Mayes, 2000; from Luyten and Fonagy, 2009, p. 369).

### **2.3.2 Attachment and Mentalizing in Type 1 Diabetes**

In order to develop a comprehensive model for understanding Type 1 diabetes from a contemporary psychodynamic perspective, it is necessary to examine the potential role played by attachment and mentalizing in the different dimensions of the illness. For this purpose, a review of the literature on attachment and Type 1 diabetes was conducted and is presented below. This review is divided into sections on the predisposing, precipitating and perpetuating factors associated with T1D. It will also be the basis for my own empirical research reported in chapters 3 to 5.

### **2.3.3.1 Predisposing Factors: The Role of Attachment in T1D Vulnerability**

As discussed in Chapter 1, both biological and environmental factors have been found to play a role in predisposing individuals to T1D. Among the biological factors is the presence of islet autoantibodies, family history, the presence of the human leukocyte antigen gene in chromosome 6, ethnicity and the presence of other autoimmune conditions (ADA, 2017).

The contribution of environmental factors to the pathogenesis of T1D is more controversial (Forlenza & Rewers, 2011; Atkinson, Eisenbarth, and Michels, 2014). However, one proposed factor is early adversity and attachment trauma in particular (Mead, 2004; Sepa, Frodi and Ludvigsson, 2005).

According to Mead's hypothesis of T1D vulnerability, disruptions in early bonding and attachment, along with other early traumatic experiences, lead to a reprogramming of the HPA axis and subsequent autonomic dysfunction (Boyce, Barr and Seltzer, 1992, cited in Mead, 2004). Based on data from previous research on the neurophysiology of stress, she argues that stress impairs HPA axis functioning and the autonomic nervous system regulatory functions, which in turn affects the immune and nervous systems. This imbalance exposes the individual to higher insulin demands, contributing to the autoimmune reaction which triggers the onset of diabetes.

Following a similar idea, Sepa, Frodi and Ludvigsson (2005) conducted an empirical study on 40 mothers of children with diabetes-related autoantibodies (DRA) to analyse the link between the presence in children of DRA– a known T1D

predisposing factor – and the attachment security of mothers. They hypothesized that, given the role of the mother's attachment security in determining her capacity to regulate the child's stress efficiently, such a link might be expected. They explored this using the "beta cell stress hypothesis" (Sepa and Ludvigsson, 2006; see Chapter 1) which claims that the presence of autoantibodies stems from the influence on the beta cells of the pancreas of a range of factors, of which psychological stress is one. As the mother's attachment security may affect her ability to help the infant down-regulate stress, they reasoned that infants of mothers with an insecure attachment would be more likely to have positive diabetes-related autoantibodies.

The researchers used the Adult Attachment Interview (AAI; George, Kaplan, Main, 1985) to compare the attachment security of two groups of mothers: 18 with positive and 32 with negative autoantibodies in their infant's blood. As expected, the positive autoantibodies group (i.e., mothers of infants with a higher biological predisposition to T1D) presented higher frequencies of insecure attachment than the negative autoantibodies group (33% versus 19%); however, this difference was not statistically significant. Given the limitations of the study (e.g., its small sample and cross-sectional design), one should not be surprised that the results were inconclusive. However, these findings provide some support for the view that the caregiver's attachment status may have an impact on T1D.

#### **2.3.3.2 Precipitating Factors: The Role of Attachment in T1D Onset**

As discussed in Chapter 1, a range of research supports the idea that psychological stress may trigger the chain of events leading to the death of beta cells



and the onset of T1D. A good example is the above-mentioned “beta cell stress hypothesis” (Sepa and Ludvigsson, 2006), which suggests that the hormonal response to psychological stress contributes to excessive demand for insulin and a resultant increase in insulin resistance. This hypothesis is supported by the findings of a large-scale longitudinal study by Sepa, Frodi, & Ludvigsson (2005; see Chapter 1)

A second formulation, the “overload hypothesis” proposed by Dahlquist (2006), suggests that the environmental triggers identified by Sepa do indeed lead to beta cell death, but by a different mechanism. She posits that psychological stress provokes beta cell hyperfunction, via an excessive release of cortisol and catecholamines, which in turn increases apoptosis, leading to beta cell death. Note that in this hypothesis, beta cell death is not linked to autoimmunity.

Following the same line of thought, it has been suggested that specific stressful experiences can be a precipitating factor in the onset of T1D. One study showed that serious negative life events in childhood (such as parental divorce or the death of a family member) were related to the presence of diabetes-related autoantibodies in children who did not have these autoantibodies in their first year of life (Nygren, Carstensen, Koch, Ludvigsson and Frostell, 2015; see Chapter 1 for a detailed summary of the study).

In reviewing the body of literature related to the “beta cell stress hypothesis”, Radobuljac and Shmueli-Goetz (2015) have argued that the child’s attachment security should be thought of as one of the mechanisms linking psychological stress and T1D onset. However, there is as yet no evidence to support this argument.

### **2.3.3.3 Perpetuating Factors: The Role of Attachment in the Course of T1D.**

The ongoing experience of T1D is the dimension that has been most studied from an attachment perspective. Given the chronic nature of T1D, the way in which individuals live with and control the disease has important consequences in terms of the frequency of acute episodes and/or complications that can occur. The role of the individual with T1D or their caregiver in determining the course of the illness has been assessed in three domains: the impact of T1D on psychosocial functioning, treatment adherence, and health outcomes.

#### **Attachment and Impact of T1D on the Mother-Child Dyad**

Again, only a handful of studies have been conducted in this area, emphasizing the need for further research. To the best of my knowledge, only one empirical study focused on children has been conducted (Moreira and Canavarro, 2016).

Moreira and Canavarro (2016) conducted a cross-sectional study in which 105 parents of children with T1D (92.4% of them mothers) answered self-report measures on attachment (ECR-RS; Fraley, Heffernan, Vicary and Brumbaugh, 2011), parenting stress (PSI-SF; Abidin, 1995) and the perceived impact of diabetes (IOF-R; Stein and Jessop, 2003). Using regression-based path analyses, they examined whether attachment anxiety and avoidance were associated with parenting stress and the perceived impact of the illness on the family. After controlling for relevant covariates (e.g., parent's education), attachment avoidance

was significantly and positively associated both with perceived impact and parenting stress, whereas attachment anxiety showed no such association. The study concluded that the relationship between attachment avoidance and parenting stress was both direct and indirect (i.e. through an increasingly negative perception of the impact of diabetes).

### **Attachment and T1D Treatment Adherence**

More extensive research has been carried out regarding treatment adherence and attachment in T1D. To my knowledge, five empirical works (Turan, Osar, Turan, Ilkova & Damci, 2003; Bazzazian and Besharat, 2012; Morris, Berry, Wearden, Jackson, Dornan and Davies, 2009; Ciechanowski et al., 2001; Ciechanowski et al., 2004) and one systematic review (Jimenez, 2017) show consistently that individual differences in adherence to treatment are related with attachment styles.

Two main issues emerged from this body of research. First, the finding that patients relying on dismissing/avoidant attachment patterns present poorer treatment adherence than others (Turan et al., 2003; Ciechanowski et al., 2001; Ciechanowski et al., 2004). Second, the idea that dismissing/avoidant patterns of attachment are associated with the issue of potential underreporting (Morris et al, 2009; Bazzazian et al., 2012). Only one study found a significant association between ambivalent attachment and several aspects of poor treatment adherence (Bazzazian et al., 2012).

Dismissing attachment was associated with poorer adherence to treatment in the study by Turan and colleagues (2003). A total of 89 patients with T1D (16-66

years old) answered self-report measures on attachment and diabetes. The attachment style was measured using the Relationship Scales Questionnaire (RSQ; Griffin and Bartholomew, 1994), coping styles were assessed by the Diabetes Coping Measure (Welch, 1994) and psychological adjustment to diabetes was measured using the Diabetes Integration Scale (ATT19; Welch, Dunn and Beeney, 1994). Finally, adherence to treatment was measured using the Diabetes-Self-Care Activities Questionnaire (Toobert and Glasgow, 1994). The results confirmed the authors' expectations: in general, patients with dismissing attachment had poorer diabetes outcomes than patients with other attachment styles. The authors suggest this might be related to the way in which patients manage their treatment and cope with the illness. For example, individuals with dismissing attachment may lack attention to bodily needs, which is key to carrying out self-care behaviours. They also highlight that other adult attachment styles, such as avoidant and fearful, may be related to poor diabetes outcomes, though probably through different mechanisms. In the case of fearful attachment, the only correlation found was with a distrust of needles, which is consistent with the early psychoanalytic assumptions outlined above.

However, a similar study by Bazzazian and Besharat (2012) produced different results. These authors recruited 300 adult participants, aged from 18-30 years old, who completed several self-report measures on attachment, illness perception, coping strategies and psychological well-being. The findings revealed no clear associations between avoidant attachment style and problems with treatment adherence. In contrast, individuals in the ambivalent attachment category showed

the highest rates of poor treatment adherence. Surprisingly, avoidant (and secure) attachment styles showed a positive adjustment to diabetes.

The authors explain their results suggesting that ambivalent individuals tend to use emotion-oriented strategies to deal with stressful situations; such behaviours have been linked in previous studies with disengagement and substance abuse (Tuncay, Musabak, Engin Gok and Kutlu, 2008). However, regarding the controversial findings on the avoidant group, the authors explain the results in terms of the reporting bias typical of this attachment organization style, as they tend to underreport physical symptoms and distress. Yet, as noted, in the study of Turan and colleagues (2003), an association between dismissing attachment and poor adherence to treatment was found.

This reporting bias, common in patients with dismissing attachment styles, was also discussed in a study conducted by Morris, Berry, Wearden, Jackson, Dornan and Davies (2009). In their research, informant-rated attachment avoidance was significantly negatively correlated with self-rated alliance (with medical staff). Individuals rated as avoidant by professionals reported poorer relationships with medical staff, however, the avoidance rated by the patients were uncorrelated with self- and informant-rated alliances. The authors link their findings to Slade's (1999) observation that people with avoidant attachment tend to minimize expressions of distress and portray themselves in overly positive terms. These individuals may, therefore, be more likely to show a positive bias in reporting the quality of their therapeutic relationships.

Consistent with this assumption, the idea that dismissing attachment style is associated with poor adherence to the treatment is supported by several studies by

Ciechanowski and colleagues (Ciechanowski et al., 2001 and 2004). These researchers studied diabetes treatment adherence in the context of healthcare provider relationships and attachment theory. In one of their studies (Ciechanowski et al., 2001), 367 adults (including T1 and T2 diabetes) completed several self-report measures on attachment, communication with the health provider and diabetes outcomes. The results showed that the link between attachment category and patient-rated quality of provider communication was significantly associated with HbA1c levels. Patients with a dismissing attachment style had notably higher HbA1c than those with secure and preoccupied attachment styles. This association was even higher if patients with dismissive attachment assessed their communication with the health provider as poor. By contrast, the group presenting secure attachment and good communication reported the best diabetes outcomes within the sample.

The same researchers (Ciechanowski et al., 2004) conducted a very similar study but this time in a population-based sample of adults (N=4,095). The results confirmed the team's previous finding that a dismissing attachment style posed the highest risk to treatment adherence. Mediation analyses were conducted to determine the extent to which the patient/health provider relationship influenced the link between attachment style and diabetes adherence or health outcomes. The researchers found that patients with a dismissing attachment style were significantly more likely to show lower adherence to aspects of treatment compared with securely attached patients. Individuals with a preoccupied attachment style were significantly less likely to have good HbA1c compared with the secure attachment cohort.

Mediational analyses showed that attachment style was significantly associated with the patient/health provider relationship. Patients with a secure attachment style showed a higher degree of collaboration with their health care provider than did patients with fearful and dismissing (but not preoccupied) attachment styles. Increased patient/health provider collaboration was also significantly associated with better adherence to treatment aspects. The relationship between dismissing attachment style and poorer adherence was mediated through the patient/health provider relationship. The prevalence of attachment styles within the sample was as follows: secure 44.1%, dismissing 35.7%, preoccupied 8.0% and fearful 12.2%.

Dismissing attachment style has been shown to be the least favourable to treatment adherence in other chronic medical conditions. Jimenez (2017) presents an exhaustive review of studies analysing the relationship between medical outcomes, attachment styles and patterns of use of the healthcare system in patients with chronic illness. He found that avoidant-dismissive attachment styles are commonly mentioned in the literature as those having the poorest healthcare utilization and adherence to treatment. By contrast, patients with preoccupied-anxious attachment styles tend to visit their doctors excessively (and sometimes unnecessarily), but also present with more complaints and require the most examinations. This brings us to the issue of health outcomes.

## **Attachment and T1D Outcomes**

The association between diabetes outcomes (for example, metabolic control) and attachment has been investigated in only one study. Rosenberg and Shields (2009) assessed attachment in 31 families (mother, father, and adolescent) using self-report measures (IPPA; Armsden & Greenberg, 1987). They found that less secure attachment, as perceived by mothers, was associated with poorer glycaemic control (as measured in terms of HbA1c), which is consistent with previous findings on treatment adherence (which is in turn related to glycaemic control, as seen in Chapter 1).

However, studies on other chronic conditions contribute further evidence to the idea that attachment insecurity is related to negative health outcomes. For example, in a study by Fischer-Fay, Goldberg, Simmons and Levison (1988) attachment was measured in the mothers of 23 infants with Cystic Fibrosis (CF) and 23 matched control were measured using Ainsworth's Strange Situation Procedure. They found that insecure infants with CF presented poorer health indicators (lower weight and lower height percentiles) than their securely attached counterparts.

Another example, this time in adults is the research conducted by McWilliams and Bailey (2010). In a large sample (N=5,645; the U.S National Comorbidity Survey sample) they found that insecure attachment styles were highly correlated with negative health outcomes. Specifically, anxious attachment styles were associated with heart-related conditions and avoidant attachment styles were also related mainly to pain-related conditions.



Thus far, it has been shown that the existing body of research supports the idea that attachment may play a significant role in health outcomes. Surprisingly, however, empirical studies on T1D from an attachment-mentalizing perspective are scarce, and even fewer are focused on children. Next, a critical discussion of the literature reviewed in this section will be presented.

### **2.3.3 Discussion**

In the previous section, studies relating T1D to attachment were reviewed. The majority of the research described addressed attachment from a behavioural perspective. None of the studies adopted a contemporary psychodynamic approach to attachment theory or included a focus on mentalizing. Additional methodological limitations include the following:

First, all of the studies discussed used categorical measures of attachment. Yet attachment has been shown to be dimensionally distributed (Fraley, Waller and Brennan, 2000). Specifically, by classifying individuals according to just one broad measure of attachment, they ignore the nuances observable in adult attachment patterns, which often conform to more than one prototype (Stein et al., 2002). To overcome these limitations, attachment researchers have now largely adopted continuous measures (Crowell, Fraley and Shaver, 1999), although some authors continue to defend a more categorical approach.

Second, some of the studies reviewed (Ciechanowski, et al 2001 and 2004; Morris et al., 2007) combined individuals with Type 1 and Type 2 diabetes. Although

the work of Ciechanowski and colleagues, for instance, is based on large samples, it considers patients with diabetes as a single homogeneous group. Other studies in the field of diabetes advise against placing the two illnesses under the same umbrella. As the table below shows, there are at least three key differences between Type 1 and Type 2 diabetes (See Figure 2.4):

**Figure 2.4: T1D and T2D Main Differences**

	TYPE I DIABETES	TYPE II DIABETES
<b>AETIOLOGY</b>	Autoimmune reaction. No more insuline production. Causes unknown.	Insuline resistance. Associated with excess body weight.
<b>ONSET</b>	Childhood	Adulthood
<b>TREATMENT</b>	Require insulin injections or insulin pump.	Not necessarily require insulin. Oral medication if required.

While in purely biological terms, it can be useful to study the two conditions together (as both relate to the same organs and hormones), from a psychosocial perspective they present very different challenges and therefore have different meanings within the subjects' internal world. Thus, there are clearly limits on how far results from studies in adults can be generalized to the experience of children with Type 1 diabetes, the focus of the present study.

Third, the research discussed focused on individuals of different ages without addressing developmental differences. For example, while adolescents are included

in some studies, there is no recognition of the fact that this stage of life may present distinct issues concerning the management of Type 1 diabetes, such as difficulties with disease control, self-management, and other complications. Infants were included in only one of the studies, which did not address T1D, and there were no studies at all of T1D in middle childhood, which is the focus of the present PhD thesis. Yet, middle childhood precedes the most challenging period for treatment management of T1D, i.e., adolescence (Daneman, Wolfson, Becker and Drash, 1981; Johnson, 1988; Ingersol, Orr, Vance and Golde, 1992). Therefore, knowledge of psychosocial features that are implicated in the course of T1D in middle childhood may help to prevent some of the risk factors that play a role in the diabetic control imbalances seen in adolescence. Puberty brings about metabolic imbalances and variations in insulin requirements due to hormonal changes and psychosocial variables, as has been conclusively shown (Hood, Peterson, Rohan, and Drotar, 2009).

In terms of adolescent T1D, these imbalances are likely to be reflected in specific behavioural patterns (i.e., relating to treatment adherence or self-management). Middle childhood is also a developmental period in which children are neither sufficiently autonomous to be wholly responsible for their treatment, nor completely dependent on their caregivers (as a pre-schooler would be). This transitional period is, therefore, key to the planning of effective T1D treatment, which is why it is the focus of the present thesis.

The fourth limitation is that most of the studies look at just one half of the caregiving dyad, whether regarding parents and children or patient and healthcare providers. In the case of T1D, it would be useful to explore how a life-threatening

condition impacts the patterns of attachment within a dyad, alongside the caregiving challenges that the illness entails. Although the best way to answer such a question would be through longitudinal research, my own studies also adopt a cross-sectional design, yet with careful consideration of both pre-morbid features and current strategies for coping with the illness. The study also, significantly, focuses on both members of the mother-child dyad and their interaction.

Finally, research into T1D has yet to examine the role of parenting and child stress in any great detail. As noted, the attachment system is a behavioral system that plays a crucial role in the regulation of stress, but in the literature reviewed, the impact of T1D-related stress in the context of an attachment relationship largely remains unaddressed. The current study aims to fill this gap.

## **2.4 General Discussion and Conclusions**

In the present chapter, I have presented and critically reviewed the literature concerning Type 1 diabetes from a psychodynamic perspective. Taken together, the extant body of work on the subject suggests an important role for the interpersonal regulation of stress in the management of T1D. Additionally, evidence suggests that attachment and mentalizing may play an important role in the understanding of T1D, as in other chronic physical conditions, and may directly inform the development of treatment and prevention efforts. However, there is currently no comprehensive model for the understanding of T1D in children, and extant research focusing on attachment and mentalizing is still very scant.

The present thesis argues that a study of the dyadic process of stress regulation (through attachment and mentalizing) in children with T1D would allow the development of a comprehensive model for informing future prevention and treatment of this population. In this sense, it is argued that an understanding of the attachment and mentalizing strategies of children and caregivers dealing with T1D would provide a gateway to better treatment and improved outcomes. Because in children this is achieved through a developmental process within the caregiver-child dyad, an interactional focus is fundamental.

The present PhD thesis aims to develop a theoretical model for the understanding of Type 1 diabetes in children and their caregivers from a contemporary psychodynamic perspective, rooted in attachment and mentalizing approaches, and to empirically test key assumptions of this model. In the remainder of this thesis, three empirical studies are presented that each address some of the key assumptions of this approach.



## **Chapter 3**

### **Attachment, Mentalizing and Diabetes Outcomes in Mother-Child Dyads**

#### **Introduction**

As discussed in Chapters 1 and 2, understanding the role of attachment and mentalizing in children with Type 1 diabetes (T1D) is vitally important to developing a comprehensive theory that can properly inform prevention and treatment for this population.

Given the growing body of evidence recognizing the role of stress and psychosocial factors in the course of T1D (see Chapter 1), a contemporary attachment approach may be particularly productive in understanding these aspects. This approach has been shown to be effective as a model for understanding other chronic illnesses related to stress in adults (Luyten, Van Houdenhove, Lemma, Target and Fonagy, 2012; Luyten and Fonagy, 2016; Maunder and Hunter, 2008) and can provide a powerful conceptual framework for understanding developmental processes (Luyten, Mayes, Target and Fonagy, 2012), such as the course of a chronic illness in middle childhood.

In children, both the regulation of stress and the diabetic treatment are evolving within the caregiver-child dyad. As seen in previous chapters, the relationship between psychosocial factors and diabetes is bidirectional: broadly speaking, diabetes both leads to psychosocial problems and psychosocial factors can cause diabetic difficulties (i.e., metabolic imbalance or lack of treatment

adherence). Additionally, in childhood this bi-directionality concerns both the child and their caregiving environment: diabetes affects and is affected by the psychosocial features of both the caregiver and child.

The theoretical framework and body of evidence provided by the contemporary attachment approach can provide an ideal perspective with which to analyze in detail the specificities of the above associations. Surprisingly, there is a paucity of research considering attachment and mentalizing in Type 1 diabetes, and much less is known about children with Type 1 and their caregivers using this approach.

In response to this, the aim of this study is to investigate the relationship between attachment, mentalizing and stress<sup>1</sup> - in both mothers and children - and the child's diabetes outcomes (i.e., diabetes-related quality of life, measured with the Padiatric Diabetes-Specific Quality of Life). It also examines the potential mediational role of stress in the relationship between attachment and diabetes outcomes and between mentalizing and diabetes outcomes, in both mothers and children.

As discussed in previous chapters, both attachment and mentalizing have been seen to influence health outcomes, mainly because of their role in the regulation of stress (Luyten and Fonagy, 2016). In the case of diabetes, it is known that stress has a negative effect on diabetes outcomes (Johnson, 1980; Fisher et al., 1982; Surwitt and Schneider, 1993; Lloyd et al., 1999; Konen et al., 1993; Wiesli et al., 2005), but the role of attachment and mentalizing in this process, as

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<sup>1</sup> Due to our observational design (as opposed to an experimental design) we will address stress mainly considering the subject's perception of their stress response (chronic activation).



key to the regulation of stress, has not been investigated. Therefore, in developing a comprehensive model with which to investigate the potential mechanisms involved, it is essential to understand how attachment and mentalizing affect diabetes.

In this respect, a further consideration is that a secure attachment environment fosters mentalizing (Fonagy, Jurist, Gergely and Target, 2002; see Chapter 2) and the activation of the attachment system may implicate the activation of neural systems that are thought to be involved in mentalizing (Fonagy and Luyten, 2009). Therefore, the mediating role of mentalizing in the relationship between attachment and diabetes outcomes was also tested.

All of the above relationships were considered for mothers and children separately, but also from an interactional perspective, as a way to understand the relationship (for example, the role of mother's stress in the relationship between child's attachment and child's diabetes outcomes) as it is known that parent's stress can affect child's diabetes outcomes (Horsch, McManus, Kennedy and Edge, 2007; Landolt et al., 2002; Northam, Anderson, Adler, Werther, and Warne, 1996; Streisand et al., 2008). Also, attachment and mentalizing in children and their caregivers have been found to be associated (Ensink and Mayes, 2010; Slade, 2005).

Taking all of the above information into account, in the present study empirical data from self-report measures in children (8 to 12-years-old) and their mothers was used to investigate the following hypotheses:

(1) Higher levels of mentalizing (i.e., child emotional awareness as assessed with

the Emotional Awareness Questionnaire) and greater attachment security (assessed with the Security Scale) would be associated with better diabetes outcomes (assessed with the Diabetes Specific Quality of Life and HbA1c).

(2) Similarly, higher maternal RF (assessed with the Parental Reflective Functioning Questionnaire) and higher maternal attachment security (assessed with Experience in Close Relationship Scale) were expected to be associated with better diabetes outcomes.

(3) Higher levels of stress (assessed with Stress in Children Questionnaire) in both children with diabetes and their mothers (assessed with the Perceived Stress Scale) was expected to be associated with poorer diabetes outcomes.

(4) Finally, the following set of hypotheses concerning mediation models was tested based on the views outlined above and in Chapter 2:

- a) Mother/child stress was expected to mediate the relationship between mother/child attachment and child diabetes outcomes.
- b) Mother/child mentalizing was expected to mediate the relationship between mother/child attachment and child diabetes outcomes.
- c) Mother/child stress was expected to mediate the relationship between mother/child mentalizing and child diabetes outcomes.
- d) Mother/child mentalizing was expected to mediate the relationship between mother/child stress and child diabetes outcomes.

This is the first study, to our knowledge, to systematically investigate key features of a contemporary attachment approach to T1D in a sample of 77 children and their mothers in Chile. In the following pages, the specific methods by which

the research and analyses were conducted will be outlined. Next, the research results will be presented, followed by a discussion of the main findings.

### **3.1 Methods**

#### **3.1.1 Participants and Procedure**

77 children and their mothers were recruited from the Juvenile Diabetes Foundation in Chile, the country's largest institution for supporting children with T1D and their families. The Foundation has the largest database of children in Chile with T1D.

An invitation letter containing the study details was sent by e-mail to the families of all the children in the database aged between 8 and 12-years-old who had been diagnosed with the condition for more than 6 months. Mothers who expressed an interest in participating received a second email with a link to a specially designed webpage containing the study's information sheets and consent forms (see Appendix A). Detailed information about the sample characteristics can be found in the results section of the present chapter. The present study was approved by the UCL Research Ethics Committee, Number 8899/001 (See Appendix B)

### 3.1.2 Measures

Mothers and children completed a range of self-report measures, described below:

**Table 3.1. Measures and Variables Study 1.**

Variable		Instrument
<b>Completed by Mothers</b>	Mother's Attachment	Experience in Close Relationship (ECR-R)
	Mother's Mentalizing	Parental Reflective Functioning Questionnaire (PRFQ)
	Mother's Stress	Perceived Stress Scale (PSS)
	Child's Diabetes-Specific Quality of Life / Diabetes Outcomes	Paediatric Quality of Life 3.2 Diabetes Module (PEDSQoL)
	Child's Metabolic Control/ Diabetes outcomes	Glycosilated Haemoglobin (HbA1c)
	Child's Diabetes outcomes	Brief questionnaire about diabetes
<b>Completed by Children</b>	Child's Attachment	Security Scale (SS)
	Child's Mentalizing	Emotional Awareness Questionnaire (EAQ)

#### Questionnaires Completed by Mothers

**Glycosylated Haemoglobin (HbA1c).** HbA1c levels provide an indication of an individual's average blood glucose concentration over the previous 2 to 3 months and this measure is considered the best marker of longer-term diabetes control. Higher values indicate poorer metabolic control, which is associated with chronic complications of vascular diseases later in life (Hanberger et al., 2008). The HbA1c exam is the most common test used in diabetes care to measure the combined effect of diet, exercise, and insulin therapy on blood glucose control in patients with

diabetes. A 1% change in HbA1c corresponds to a 30 mg/dL change in mean blood glucose level (Goldstein, Little, et al., 2004). Therefore, HbA1c is considered an indicator of diabetes control. A common target level is 6.5%. In the present study, mothers were asked to provide the last three recorded HbA1c levels for their children and the mean was used for the analysis.

**Brief Diabetes Questionnaire.** Used in conjunction with the HbA1c data as a measure of diabetes outcomes, this 7-item questionnaire was developed for the current study to assess the level of diabetes complications in the last year (for example, hospitalisations or loss of consciousness).

**Socioeconomic Status Survey (Chilean National Institute of Statistics, 2011).**

The Socioeconomic Status Survey was developed by the National Institute of Statistics in Chile (INE) to assess a participant's socioeconomic status. Participants are asked to select options from lists of goods, income and education levels; each option chosen by a participant adds points to a total score which corresponds with one quintile within a range from 0 to 1000. (High: from 823 to 1000; Middle: from 543 to 823; Middle low: from 341 to 543; Poverty: from 105 to 341; Extreme Poverty: from 0 to 105) (INE, 2011).

**The Chilean version (Spencer, Guzmán, Fresno and Ramos, 2013) of the Experience in Close Relationships Scale - Revised version (ECR-R; Brennan et al., 1998).** This self-report questionnaire assesses attachment styles in adults. It consists of 36 items, each scored using a 7-point Likert format, assessing two

dimensions underlying adult attachment: attachment *anxiety* and attachment *avoidance*, with 18 items on each scale. An example from the Anxiety scale is: “I am quite concerned about the possibility of losing my partner” and from the Avoidance scale: “I prefer not to show my partner my feelings”. This scale has shown high reliability with a Cronbach’s alpha of  $\alpha=.78$  in the Anxiety scale, and in the Avoidance scale a score of  $\alpha=.84$  (Wei et al., 2007). The Chilean validation of the scale showed to be reliable with an  $\alpha=.81$  for the Anxiety scale and  $\alpha=.84$  for the Avoidance scale (Spencer et al., 2013). In the present study, Cronbach’s alphas were  $\alpha=.73$  for the Anxiety scale and  $\alpha=.71$  for the Avoidance scale.

### **The Chilean version (Santelices, in press) of the Parental Reflective**

**Functioning Questionnaire (PRFQ; Luyten et al., 2017).** A multidimensional measure of Parental Reflective Functioning (PRF), this scale contains 18 items based on descriptions and examples in the Reflective Functioning Manual for the Adult Attachment Interview (AAI; Fonagy et al., 1998); the Reflective Functioning Manual for the Parental Development Interview (PDI; Slade et al., 2004) and the Reflective Function Rating Scale (Fonagy, Target, Steele and Steele, 1998). Each item in the PRFQ-1 is scored on a 7-point Likert scale, where 1 is *strongly disagree* and 7 *completely agree*, and they capture three key dimensions of PRF: (1) Pre-Mentalizing (PM): the inability to enter the subjective world of the child in particular and malevolent attributions (e.g., “My child cries around strangers to embarrass me”), (2) Certainty about Mental States (CMS): the capacity of recognising the opacity of mental states (low levels of CMS reflect a lack of certainty, while the highest levels reflect a tendency to be overly certain), and (3) Interest and Curiosity

about Mental States (IC): in this scale very high scores represent intrusive hyper-mentalizing and low scores show the absence of interest and curiosity about the child's mental state. Estimates of internal consistency (Cronbach's alpha) were: .70, .82, and .75 for PM, CMS, and IC, respectively (Luyten et al., 2017).

Cronbach's alphas in this study were PM  $\alpha$ =.73; CMS  $\alpha$ =.77, and IC  $\alpha$ =.72.

**The Chilean version (Calderon-Carvajal, Gómez, Lopez, Otarola and Briceño, 2017) of the Perceived Stress Scale (PSS; Cohen et al., 1983; Cohen and Williamson, 1988).** The PSS is a 14-item questionnaire where participants are asked to report how often they thought or felt a particular way during the past month, from 1 ('never') to 4 ('very often'), with higher scores representing higher levels of perceived stress. Questions are formulated with no specific topics so that they are understandable for any cultural sub-group. The instrument has shown good validity. The validation study (Cohen et al., 1983) reported a coefficient alpha reliability of .84, .85, .86 for each sample in which the measure was administered (two student samples and one smoking-cessation sample). There were no significant differences between females and males and test-retest correlations after 6 weeks were .85 for the student sample. The measure was shown to be valid for the Chilean population (Calderón-Carvajal et al., 2017). In the present study, the PSS showed a Cronbach's alpha of  $\alpha$ =.79.

**The Chilean version (Varni, 1999) of the Paediatric Quality of Life Inventory Diabetes Module 3.2 Parent-Report (PEDS-QoL 3.2 Diabetes Module; Varni et al., 2003).** This scale measures the child's Parent-Reported Diabetes Specific Quality of Life. It assesses how well the illness has been integrated in the child's

life and concerns several dimensions of diabetes care, which are reflected on the subscale. In this sense, the PEDSQoL can be considered an indicator of diabetes outcomes. It consists of 28 items divided into four subscales: (1) Diabetes Symptoms (11 items), (2) Treatment Adherence (11 items), (3) Diabetes Concerns (3 items; e.g., in the last month “It has been a problem for my child being worried about future diabetes complications” ), and (4) Diabetes Communication (3 items; e.g., in the last month “It has been a problem for my child to explain his illness to other people”). Responses are on a 5-point Likert scale (ranging from *never a problem* to *almost always a problem*) with higher scores meaning fewer problems (therefore, higher Diabetes Specific Quality of Life). Most scales in this measure exceeded the reliability standard of .70, with  $\alpha$ -coefficients for each subscale, as follows: Diabetes Symptoms (DS) .81 ; Treatment Adherence (TA) .68; Worry (W) .81; Communication (C) .84. In the present study, Cronbach’s alphas on the PEDSQoL were: DS  $\alpha$ =.82; TB  $\alpha$ =.74; TA  $\alpha$ =.73; W  $\alpha$ =.86; and C  $\alpha$ =.87.

### **Questionnaires Completed by Children**

**The Latin-American version (Cárdenas-Fernández, in press) of the Security Scale (SS; Kerns et al., 1996).** A 15-item questionnaire that assesses a child’s perception of attachment security in relation to their mother. Each item presents a forced choice (Harter, 1982) between two statements whereby the subject rates “Sort of true for me” or “Really true for me”. Items are scored from 1 to 4, with a higher score indicating greater perception of security. The SS was designed specifically for middle childhood and early adolescence and items assess the following: (1) the degree to which children believe a particular attachment figure



(the mother in this case) is responsive and available, (2) the child's tendency to rely on the attachment figure in times of stress, and (3) children's reported ease and interest in communicating with the attachment figure. Its reliability has been proved to be high. In validation studies, the SS demonstrated high test-retest stability ( $r=.75$ ; 14 days) and Cronbach's alpha ranged from .84 to .88 in two studies with 10 to 12-year-old children who also participated in a follow-up study 2 years later (Kerns et al., 2001) and completed projective measures of attachment, such as the Separation Anxiety Test (SAT; Resnick, 1993). Both ratings and classifications on the SAT were related with SS scores (e.g., children reporting greater security to their mother in the SS were less dismissive and had more coherent discourse during the SAT interview). In this study, the SS Cronbach's alpha was  $\alpha=.77$ .

**The Latin-American version (Ordóñez, Prado-Gascó, Villanueva and González, 2016) of the Emotional Awareness Questionnaire (EAQ-30; Rieffe et al., 2008).** The questionnaire was used as a proxy for mentalizing in children. The EAQ-30 has been designed for children from 8-years-old and has 30 items, measuring 6 features of emotional awareness: (1) Differentiation of Emotions (DE) (i.e., the ability to differentiate between emotions and locate their antecedents; item sample: "It is difficult to know whether I feel sad, or angry, or something else"), (2) Verbal Sharing (VS) (i.e., the capacity to communicate emotions; item sample: "I find it hard to talk to anyone about how I feel"), (3) Not Hiding Emotions (NE) (i.e., the tendency not to keep one's emotional experiences hidden from others; item sample: "Other people don't need to know how I am feeling"), (4) Bodily Awareness

(BA) (attention to the physiological aspects of the emotional experience and awareness that emotions are accompanied by bodily symptoms; item sample: “When I feel upset, I can also feel it in my body”), (5) Attending to Other People’s Emotions (OTE; item sample: “It is important to know how my friends are feeling”), and (6) Analysis of Own Emotions (OWE; item sample: “When I am angry or upset, I try to understand why”). Responses are rated on a 3-point scale (1 = never, 2 = sometimes, 3 = often). Reliability was established from two different age group samples, primary and secondary school ages and Cronbach’s alpha for each scale on both samples were established as follows: Differentiation of emotions: .67, .74; Verbal sharing: .68, .77; Not hiding: .68, .76; Bodily awareness: .64, .74; Others’ emotions: .65, .77; Own emotions: .65, .77. In the present study, Cronbach’s alpha of the EAQ subscales were as follows: DE  $\alpha$ =.70; VS  $\alpha$ =.71; NH  $\alpha$ =.73; BA  $\alpha$ =.69; OTE  $\alpha$ =.74; OWE  $\alpha$ =.75.

**The Chilean version (Caqueo-Urizar, Urzúa and Osika, 2014) of the Stress in Children (SiC) (Osika et al., 2007).** The SiC is a 21-item questionnaire for school-age children designed to assess perceived distress, levels of well-being and aspects of coping and social support. Participants are asked to rate how often they thought or felt a certain way during the last month, ranging from *never* to *very often*, with higher scores meaning higher levels of stress. The SiC demonstrates high internal consistency with a Cronbach’s alpha-coefficient of .79 for the complete test score, and .79, .67 and .62 for the three subscales: Lack of well-being (LWB), Distress (D) and Lack of Social Support (LSS), respectively). The SiC showed to be reliable in the Chilean population, for the three subscales (LWB, D

and LSS) with a Cronbach's alpha-coefficient of .80, .77 and .69 respectively (Caqueo-Urizar et al., 2014). The SiC Cronbach's alpha on the present study were: LWB  $\alpha$ =.70; D  $\alpha$ =.66; LSS  $\alpha$ =.67.

### **3.2 Data Analysis**

First, zero-order-correlations were calculated between all study variables and the socio-demographic variables for the total sample and for boys and girls separately. Second, bivariate correlations were performed between independent and outcome variables, and partial correlations controlling for demographics were performed when relevant (as detailed below). All data were coded and analysed using SPSS 24. Third, mediation analyses were conducted in SPSS 24 using Hayes (2012) macro PROCESS, which produces bootstrapping procedures to generate random sampling data. The goal of this model was to investigate the total (c) and direct effects (a, b, c'), reflected by the unstandardized regression coefficient, and significance between the independent and dependent variables in each model. The model also investigated the indirect effect (IE) obtained from the product of coefficients ( $a \times b$ ), which indicates the change in the predictor variable levels for every unit change in the outcome variable levels, that is mediated by the proposed mediator.

For this study, data was resampled 5.000 times (Preacher and Hayes, 2008). Significant IE (mediation) were assumed when the upper and lower level of the 95% confidence intervals did not contain zero (Hayes, 2018).

### 3.3 Results

#### 3.3.1 Demographic Features

**Table 3.2. Demographic Information Study 1**

	<i>Mean (SD) or %</i>	<i>n</i>		<i>Mean (SD) or %</i>	<i>n</i>
<b>Mothers information</b>			<b>Children information</b>		
<b>Age (years)</b>	38.95 (7.07)	77	<b>Age (years)</b>	10.12 (1.57)	77
<b>Educational Level (%)</b>			<b>Sex (%)</b>		
<i>Basic/elementary school</i>	2.6	2	<i>Female</i>	55.8	43
<i>Secondary school</i>	14.3	11	<i>Male</i>	44.2	34
<i>Technical education incomplete</i>	9.1	7	<b>Time since diabetes onset (months)</b>	38.77 (31.80)	77
<i>Technical education complete</i>	23.4	18	<b>Hba1c</b>	8.05 (1.26)	77
<i>University incomplete</i>	14.3	11			
<i>University complete</i>	27.3	21			
<i>Postgraduate studies</i>	9.1	7			
<b>Socioeconomic level (%)</b>					
<i>High</i>	44.2	34			
<i>Middle</i>	48.1	37			
<i>Low-middle</i>	6.5	5			
<i>Poverty</i>	1.3	1			

Table 3.2 presents the demographic data for the study sample. The mean age of mothers was 39-years-old with a standard deviation (SD) of 7. Most presented a middle or high socioeconomic status and the majority were relatively highly educated.

The mean age of children was 10-years-old and the average time since T1D diagnosis was 39 months; just over half of the children (55.8%) were female. Mothers were asked to report their child's previous three exams of glycosylated hemoglobin (HbA1c). As explained in Chapter 1, children with T1D are asked to measure their HbA1c levels every three months, therefore, exams provided by mothers approximately reflect the last 9 months of diabetes control. The mean level of HbA1c was 8%, with a SD of 1.27. Considering that the common target level of HbA1c is 6.5% (NICE, 2015) it can be argued that the mean HbA1c levels in this sample reflect, on average, a good diabetic control. Additionally, the SD reflects low variability in HbA1c levels among the children in this sample (see Table 3.1).

None of the study variables were significantly correlated with any of the demographic features either in mothers or in children, with two small exceptions: *socioeconomic status* of the mother and *child's age* were found to be significantly correlated with some dimensions of the mentalizing measures in both mothers and children (PRFQ and EAQ). Specifically, a positive correlation was found between *socioeconomic status* of mothers and PRFQ *interest and curiosity in mental states* for the total sample of mothers ( $r=.28$ ,  $p<.05$ ), as well as for mothers of girls separately ( $r=.39$ ,  $p<.05$ ). Hence, mothers of girls with higher socioeconomic status tended to show somewhat higher levels of IC in their child's mind, particularly in girls. *Socioeconomic status* of mothers was also found to be negatively correlated with *bodily awareness* ( $r= -.33$ ,  $p=.004$ ) for the total sample and for girls ( $r= -.44$ ,  $p=.01$ ) specifically; and positively correlated with *not hiding emotions* ( $r=.36$ ,  $p=.04$ ) and *analysis of own emotions* ( $r=.35$ ,  $p=.04$ ), also in girls only.

In other words, girls that presented higher *socioeconomic status* showed better *analysis of their own emotions* and tended to *not hide their emotions*; however, they presented lower *bodily awareness*. The latter may reflect that sociocultural aspects play a role in body representation. For example, studies have found that “physical self-esteem” tends to be lowest among girls of higher socioeconomic status (O’Dea and Caputi, 2001). Also, weight issues are more prevalent among females of higher socioeconomic status (Wardle and Marsland, 1990; Walters and Kendler, 1995).

A negative correlation was found between *child’s age* and *interest and curiosity in mental states* within the total sample ( $r=-.30$ ,  $p=.007$ ) and, this time, also for girls’ and boys’ mothers separately ( $r= -.36$ ,  $p=.03$  and  $r= -.31$ ,  $p<=.04$ ). *Child’s age* was also positively correlated with *attending to other people’s emotions* in both girls ( $r=.47$ ,  $p=.006$ ) and boys ( $r=.33$ ,  $p=.038$ ) and negatively correlated with *analysis of own emotions* ( $r= -.35$ ,  $p=.048$ ). These findings could imply that IC decreases with age, and that attending to other people’s emotions becomes better over the years, which is consistent with findings in the literature (Luyten, Mayes, Nijssens and Fonagy, 2017). Surprisingly, when *child’s age* was higher, *analysis of own emotions* was lower which could imply that the emotions experienced become more complex with age and the acknowledgment of the complexity of the emotions gives rise to a feeling of being less competent to deal with them (see Appendix C for demographics correlation matrix).

### 3.3.2 Study Variables Correlations

#### 3.3.2.1 Attachment and Diabetes

##### **Mothers**

Although both attachment *avoidance* and *anxiety* in the total sample and the PEDSQoL total were, as expected, negatively correlated ( $r = -.50, p < .01$ ;  $r = -.42, p < .01$ , respectively) and, because of this, higher levels of *avoidance* and *anxiety* in attachment relationships in mothers were related to lower diabetes-related quality of life in their children, important gender differences emerged.

As Table 3.3. shows, the highest correlations were observed for the *symptoms* and *treatment adherence* subscales, particularly in boys. For boys, attachment *avoidance* was significantly correlated with the *treatment adherence* and *symptoms* subscales, while attachment *anxiety* only with *symptoms*. In girls, by contrast, attachment *avoidance* correlated significantly only with *symptoms*, whereas attachment *anxiety* was negatively correlated with *treatment adherence*, *symptoms* and a clear trend to be negatively correlated with the *concerns* and *communication* scales as well, although these two latter trends were not significant.

Regarding the diabetes outcomes indicator HbA1c, again, an important gender difference was found. In mothers of girls, attachment *avoidance* was negatively correlated with HbA1C ( $r = -.33, p < .01$ ), implying that good diabetes outcomes were associated with more *avoidance* in attachment relationships. In contrast, in the group of boys' mothers there was a positive trend between HbA1c

and attachment *avoidance* ( $r=.29$ ,  $p<.06$ ), which implies that better diabetes outcomes were associated with less *avoidance*. Surprisingly, attachment *anxiety* was not significantly correlated with HbA1c. Although the limited range in HbA1C scores might be in part responsible for these unexpected findings, together, these findings seem to point to important gender differences in relation to diabetes outcomes in girls versus boys and a differential role of attachment *anxiety* and *avoidance* in mothers in this respect.

### **Children**

Gender differences were also found regarding results for the measures completed by the children. Consistent with expectations, a positive correlation was found between child attachment security and PEDSQoL total in the total sample ( $r=.20$ ,  $p<.05$ ) meaning that more secure attachment was related with higher diabetes *quality of life*. In boys, as expected, a negative correlation was also found between HbA1c and attachment security ( $r= -.35$ ,  $p<.05$ ); namely, better diabetes outcomes were associated with higher attachment security. In contrast, however, in girls, attachment security did not show any significant correlation with diabetes variables, which was against expectations (see Table 3.3 for a complete list of correlation coefficients between attachment and diabetes measures).



**Table 3.3. Correlations between Child's Attachment (SS), Mother's Attachment (ECR) and Diabetes Outcomes (PEDSQoL and HbA1c).**

	PEDSQoL Dimensions					Hba1c
	Concern	Communication	Treatment	Symptoms	Total	
<b>All ECR Scale</b>						
	-.113	-.044	-.273**	-.354**	-.502**	-.003
<i>Avoidance</i>						
<i>Anxiety</i>	-.203*	-.241*	-.342**	-.425**	-.420**	-.022
<b>Security Scale</b>	.217*	.066	.155	.176	.203*	-.166
<b>Boys ECR Scale</b>						
	-.093	-.043	-.308*	-.357*	-.322*	.291
<i>Avoidance</i>						
<i>Anxiety</i>	-.134	-.256	-.195	-.289*	-.285*	-.017
<b>Security Scale</b>	.190	-.030	.196	.178	.194	-.358*
<b>Girls ECR Scale</b>						
	-.105	-.021	-.218	-.350*	-.261	-.334*
<i>Avoidance</i>						
<i>Anxiety</i>	-.229	-.204	-.476**	-.597**	-.548**	-.056
<b>Security Scale</b>	.217	.145	.027	.126	.166	.096

Note: \*  $p < .05$ , \*\*  $p < .01$

### 3.3.2.2 Mentalizing and Diabetes

Correlations between mentalizing variables (PRFQ scales and EAQ scales) and diabetes variables (HbA1c and PEDSQoL) were performed controlling for *socioeconomic level* and *child's age* (see section on demographic features above).

#### **Mothers**

As expected, a negative significant correlation was found between PRFQ *interest and curiosity in mental states* and *diabetes communication* ( $r = -.27$ ,  $p < .05$ ) for the total sample, and also for the group of girls ( $r = -.42$ ,  $p < .05$ ), but not in boys.

PRFQ *certainty of mental states* was also found to be negatively correlated with *diabetes symptoms* and with *treatment adherence*, which was consistent with expectations ( $r = -.23$ ,  $p < .05$  and  $r = -.27$ ,  $p < .05$  respectively). However, although there were several correlations in the expected direction between the PRFQ subscales and *quality of life*, no other correlations reached significance. Hence, PRF, at least as measured with the PRFQ, seemed to be less important in this context compared to parent and infant attachment. Surprisingly, none of the PRFQ subscales correlated significantly with HbA1c. However, again the limited range in HbA1c levels may be playing a role in this respect.

### **Children**

As expected, EAQ total was positively correlated with PEDSQoL total ( $r = .28$ ,  $p < .05$ ) and *treatment adherence* ( $r = .30$ ,  $p < .05$ ) for the total sample. Looking at the EAQ subscales, *communication of emotions* correlated positively with *treatment adherence* ( $r = .28$ ,  $p < .05$ ) and *differentiation of emotions* correlated positively with PEDSQoL total and *diabetes communication* ( $r = .24$ ,  $p < .05$  and  $r = .24$ ,  $p < .05$ , respectively).

Yet, again, an important gender difference emerged here, as mentalizing capacities seemed to be particularly related to *quality of life* and HbA1c in boys, but not in girls. Specifically in boys, several dimensions of the EAQ were found to be positively correlated with diabetes indicators, as expected. However, these associations were not found for the group of girls. Thus, in the group of boys EAQ total was found to be positively correlated with PEDSQoL total, *diabetes communication* and *treatment adherence* ( $r = .51$ ,  $p < .01$ ;  $r = .42$ ,  $p < .05$ ;  $r = .57$ ,  $p < .01$ ,

respectively). Regarding EAQ subscales specifically, in boys, *not hiding emotions* was positively correlated with PEDSQoL total, *diabetes communication*, *diabetes concerns* and *treatment adherence* ( $r=.45$ ,  $p<.01$ ;  $r=.37$ ,  $p<.05$ ;  $r=.35$ ,  $p<.01$ ;  $r=.46$ ,  $p<.01$  respectively). *Differentiation of emotions* was positively correlated with PEDSQoL total, *diabetes communication* and *treatment adherence* ( $r=.33$ ,  $p<.05$ ;  $r=.32$ ,  $p<.05$ ;  $r=.43$ ,  $p<.05$ ). *Communication of emotions* was positively correlated with PEDSQoL total, *diabetes communication*, *treatment adherence* and *diabetes symptoms* ( $r=.52$ ,  $p<.01$ ;  $r=.36$ ,  $p<.05$ ;  $r=.60$ ,  $p<.01$ ;  $r=.35$ ,  $p<.05$ ). Moreover, *communication of emotions* was negatively correlated with HbA1c, which was coherent with expectations ( $r= -.34$ ,  $p<.05$ ).

Therefore, particularly the capacity to *differentiate emotions*, to *verbally share emotions*, and to *not hide emotions*, were related to diabetes outcomes in boys. Some of these correlations were very high (e.g,  $r=.61$  between the capacity to *verbally share emotions* and diabetes *treatment adherence*). Somewhat surprisingly, *bodily awareness* was not correlated with any diabetes outcomes variable in boys, while in girls, in contrast, *bodily awareness* was the only subscale that was related to diabetes *quality of life* and diabetes *communication* ( $r=-.35$ ,  $p<.05$ ). In girls, no other significant correlations were found between EAQ dimensions and diabetes variables, which was against expectations (see Table 3.3 below for all correlations)

**Table 3.4. Correlations Between Child's Mentalizing (EAQ), Mother's Mentalizing (PRFQ) and Diabetes Outcomes (PEDSQoL and HbA1c) Controlling for Socioeconomic Level and Child's Age**

	PEDSQoL Dimensions					Hba1c
	Concerns	Communication	Treatment	Symptoms	Total	
<b>All</b>						
<b>PRFQ</b>						
<i>Interest and Curiosity in Mental States</i>	.099	-.272*	-.094	-.040	-.093	-.088
<i>Certainty of Mental States</i>	-.055	-.007	-.274*	-.237*	.033	-.144
<i>Pre-Mentalizing Modes</i>	.023	.064	-.029	-.158	-.070	.064
<b>EAQ</b>						
<i>Differentiation of emotions</i>	.098	.240*	.206	.151	.244*	-.118
<i>Verbal sharing of emotions</i>	-.038	.060	.287*	.205	.229	-.174
<i>Bodily awareness</i>	-.055	-.062	.174	.184	.133	-.072
<i>Not hiding emotions</i>	.050	.142	.183	.179	.186	-.155
<i>Attending to other people's emotions</i>	.133	.063	.058	-.065	.040	.127
<i>Analysis of own emotions</i>	-.035	.163	.025	-.037	.034	-.185
<i>Total</i>	.049	.199	.303*	.214	.286*	-.191
<b>Boys</b>						
<b>PRFQ</b>						
<i>Interest and Curiosity in Mental States</i>	.247	-.100	.048	.067	.087	-.110
<i>Certainty of Mental States</i>	-.066	.038	.244	-.273	-.012	-.275
<i>Pre-Mentalizing Modes</i>	-.131	-.173	-.247	-.172	-.247	.158
<b>EAQ</b>						
<i>Differentiation of emotions</i>	.110	.329*	.431*	.137	.334*	-.102
<i>Verbal sharing of emotions</i>	.201	.363*	.606**	.355*	.529**	-.344*
<i>Bodily awareness</i>	.064	.219	.225	.255	.267	-.127
<i>Not hiding emotions</i>	.357*	.372**	.465**	.252	.456**	-.165
<i>Attending to other people's emotions</i>	.073	.081	.162	-.025	.090	.266
<i>Analysis of own emotions</i>	-.116	-.019	-.048	.005	-.050	-.092
<i>Total</i>	.211	.427*	.572**	.317	.511**	-.194
<b>Girls</b>						
<b>PRFQ</b>						
<i>Interest and Curiosity in Mental States</i>	.006	-.429*	-.270	-.253	-.327	.006
<i>Certainty of Mental States</i>	-.042	-.101	.304	-.196	.068	.084
<i>Pre-Mentalizing Modes</i>	.134	.274	.247	-.107	-.170	-.138
<b>EAQ</b>						
<i>Differentiation of emotions</i>	.039	.130	-.084	.262	.113	-.114
<i>Verbal sharing of emotions</i>	-.350	-.186	-.117	.000	-.152	-.122
<i>Bodily awareness</i>	-.224	-.356*	.137	-.007	-.076	-.043
<i>Not hiding emotions</i>	-.281	-.060	-.205	.045	-.185	-.158
<i>Attending to other people's emotions</i>	.180	.014	-.098	-.149	-.053	.035
<i>Analysis of own emotions</i>	.000	.208	-.030	-.172	.009	-.201
<i>Total</i>	-.199	-.064	-.144	.028	-.101	-.199

Note: \* p < .05, \*\* p < .01

### 3.3.2.3 Stress and Diabetes

#### **Mothers**

Consistent with expectations, PSS was negatively correlated with PEDSQoL total, *treatment adherence* and *diabetes symptoms* in the total sample ( $r=-.40$ ,  $p<.01$ ;  $r=-.47$ ,  $p<.01$ ;  $r=-.36$ ,  $p<.01$ ). However, important gender differences emerged in the relationship between maternal stress and diabetes outcomes.

In girls, PSS and HbA1c were negatively correlated ( $r=-.41$ ,  $p<.05$ ), implying that when the mother's stress levels were higher, diabetes control was better in girls, which was against expectations.

In contrast, in boys there was a positive trend towards significant in the relationship between PSS and HbA1c ( $r=.27$ ,  $p<.10$ ) which means the opposite, that in boys, maternal stress is related with poorer diabetes control.

Also, the relationship between PSS and PEDSQoL presented differences between boys and girls. In boys, PSS was, as expected, negatively correlated with PEDSQoL total, *diabetes communication*, *treatment adherence* and *symptoms* ( $r=-.32$ ,  $p<.05$ ;  $r=-.33$ ,  $p<.05$ ;  $r=-.60$ ,  $p<.01$ ;  $r=-.44$ ,  $p<.01$ , respectively). Conversely, in girls PSS correlated negatively only with *treatment adherence* ( $r=.29$ ,  $p<.05$ ).

#### **Children**

Yet again, gender differences were found in the results. First, in the total sample, consistent with expectations, *lack of well-being* negatively correlated with *treatment adherence* ( $r=-.23$ ,  $p<.05$ ) in the total sample. In girls, surprisingly, none of the SiC scales correlated significantly with PEDSQoL dimensions, and in boys a

negative correlation was found between *treatment adherence* and *lack of well-being* ( $r=-.37$ ,  $p<.05$ ), implying that in boys, higher levels of stress may be associated with lower diabetes-specific *quality of life*, which is consistent with expectations.

One unexpected result was that none of the SiC scales was correlated significantly with HbA1c, either in boys or girls (see Table 3.5)

**Table 3.5. Correlations Between Child's Stress (SiC), Mother's Stress (PSS) and Diabetes Outcomes (PEDSQoL and HbA1c)**

	PEDSQoL Dimensions					HbA1c
	Concern	Communication	Treatment	Symptoms	Total	
All						
Stress in Children						
Distress	.045	-.004	-.131	-.074	-.080	.179
Lack of Well-being	.094	-.081	-.226*	-.068	-.129	.140
Lack of Social Support	.005	-.105	-.173	-.021	-.106	.168
Perceived Stress	-.086	-.073	-.477**	-.363**	-.402**	.013
Boys						
Stress in Children						
Distress	-.033	-.252	-.260	-.053	-.188	.153
Lack of Well-being	.071	-.215	-.369*	-.094	-.225	.142
Lack of Social Support	.110	-.098	-.230	.092	-.057	.179
Perceived Stress	-.191	-.339*	-.607**	-.441**	-.556**	.274
Girls						
Stress in Children						
Distress	.164	.235	.067	-.068	.097	.201
Lack of Well-being	.097	.041	-.033	-.048	-.012	.158
Lack of Social Support	-.134	-.121	-.105	-.213	-.185	.155
Perceived Stress	.070	.199	-.295*	-.234	-.176	-.416*

Note: \*  $p < .05$ , \*\*  $p < .01$

### 3.3.3 Mediation Analyses

Mediation analyses were performed to test the indirect effect of potential mediators in the relationships between the independent variables (child/mother attachment, child/mother mentalizing, and child/mother stress) and the outcome variable (child's diabetes outcomes), separately for boys and girls. Considering the theory reviewed in Chapters 1 and 2, and taking into account the results from the correlational analyses, both child's and mother's features and the interaction between them were tested through mediation analyses. In this way, the influence on diabetes outcomes of mother's features mediated by child's features and vice versa (for example, the effect of child's attachment on diabetes outcomes via mother's stress) were evaluated.

When considering the direction of the obtained correlations, although some mediation effects could be anticipated, we decided to test all mediation models that could be meaningful from a theoretical point of view, for the sake of comprehensiveness. As discussed previously in this thesis, secure attachment fosters mentalizing (Fonagy et al., 2002) and insecure attachment leads to poor mentalizing (Fonagy and Luyten, 2009). In addition, the attachment system has a direct effect on the stress response (Gunnar and Quevedo, 2007) and stress is regulated in a cooperative process in relation to attachment figures (Luyten et al., 2015; Sbarra and Hazan, 2008). Thus, there may be a bi-directional relationship between mentalizing and stress, as stress may lead to poor mentalizing by switching from a reflective to an automatic processing of social information, and poor mentalizing leads to stress by impairments in the interpretation of social cues

(e.g., misunderstandings) and resulting interpersonal problems (Fonagy et al., 2002). Moreover, both caregiver and child features are related in these processes (Slade, 2005). Considering the above, for each set of hypotheses concerning mediation, all the possible combinations between mother's and child's features were tested.

Another reason to perform all the possible mediation analyses was to identify the potential indirect effect of some variables. Indeed, even in the absence of a direct relationship between the independent and dependent variable, they might be associated through a third, so-called intervening variable. As a result, 16 different mediation models testing the set of hypotheses mentioned at the start of the present chapter were run. Additionally, they were analysed separately for boys and girls, as important gender differences had emerged from previous analyses. Total PEDSQoL scores were selected as the dependent variable in all these analyses because HbA1c levels showed limited variance in the present sample. Table 3.6 shows all the mediation models tested using Hayes (2012) macros PROCESS for SPSS 24.

**Table 3.6. Mediational Analysis Performed.**

	<i>Predictor (X)</i>	<i>Outcome (Y)</i>	<i>Mediator (M)</i>
<i>Attachment and Diabetes via Stress</i>	Mother's Attachment (ECR)	Diabetes Outcomes (PEDSQoL)	Mother's Stress (PSS)
	Mother's Attachment (ECR)	Diabetes Outcomes (PEDSQoL)	Child's Stress (SiC)
	Child's Attachment (SS)	Diabetes Outcomes (PEDSQoL)	Child's Stress (SiC)
	Child's Attachment (SS)	Diabetes Outcomes (PEDSQoL)	Mother's Stress (PSS)
<i>Mentalizing and Diabetes via Stress</i>	Mother's Mentalizing (PRFQ)	Diabetes Outcomes (PEDSQoL)	Mother's Stress (PSS)
	Mother's Mentalizing (PRFQ)	Diabetes Outcomes (PEDSQoL)	Child's Stress (SiC)
	Child's Mentalizing (EAQ)	Diabetes Outcomes (PEDSQoL)	Child's Stress (SiC)
	Child's Mentalizing (EAQ)	Diabetes Outcomes (PEDSQoL)	Mother's Stress (PSS)
	Mother's Attachment (ECR)	Diabetes Outcomes (PEDSQoL)	Mother's Mentalizing (PRFQ)



<i>Attachment and Diabetes via Mentalizing</i>	Mother's Attachment (ECR)	Diabetes Outcomes (PEDSQoL)	Child's Mentalizing (EAQ)
	Child's Attachment (SS)	Diabetes Outcomes (PEDSQoL)	Child's Mentalizing (EAQ)
	Child's Attachment (SS)	Diabetes Outcomes (PEDSQoL)	Mother's Mentalizing (PRFQ)
<i>Stress and Diabetes via Mentalizing</i>	Mother's Stress (PSS)	Diabetes Outcomes (PEDSQoL)	Mother's Mentalizing (PRFQ)
	Mother's Stress (PSS)	Diabetes Outcomes (PEDSQoL)	Child's Mentalizing (EAQ)
	Child's Stress (SiC)	Diabetes Outcomes (PEDSQoL)	Child's Mentalizing (EAQ)
	Child's Stress (SiC)	Diabetes Outcomes (PEDSQoL)	Mother's Mentalizing (PRFQ)

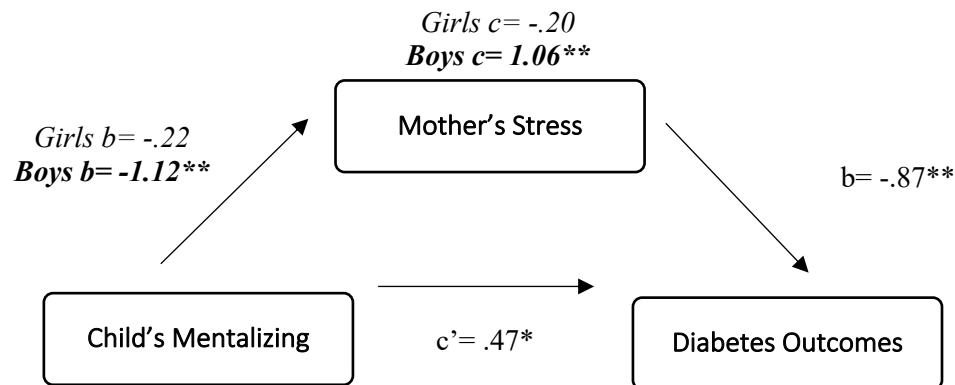
### Attachment and Diabetes via Stress

The results of the mediation analyses on both child's and mother's attachment on diabetes outcomes through the effect of both child's and mother's stress were non-significant, either in boys or girls.

### Mentalizing and Diabetes via Stress

Regarding the indirect role of both *mother's and child's stress* in the relationship between *child's mentalizing* and *child's diabetes outcomes*, as shown in Figure 3.1, only *mother's stress* showed to have a mediation effect ( $a*b = .37$ ,  $SE = .20$ ) with the 95% CI above zero (.14 to .72). The mediation analysis suggests that *mentalizing* indirectly influences *diabetes outcomes* through its effect on *mother's stress*. As can be seen in Figure 3.1, boys that presented higher levels of *mentalizing* had better *diabetes outcomes* and their mothers presented decreased levels of *stress*. Although the above was found only in boys, this is consistent with the correlational analyses.

**Figure 3.1. Mediation of Relationship Between Child's Mentalizing and Diabetes Outcomes Through Mother's Stress.**

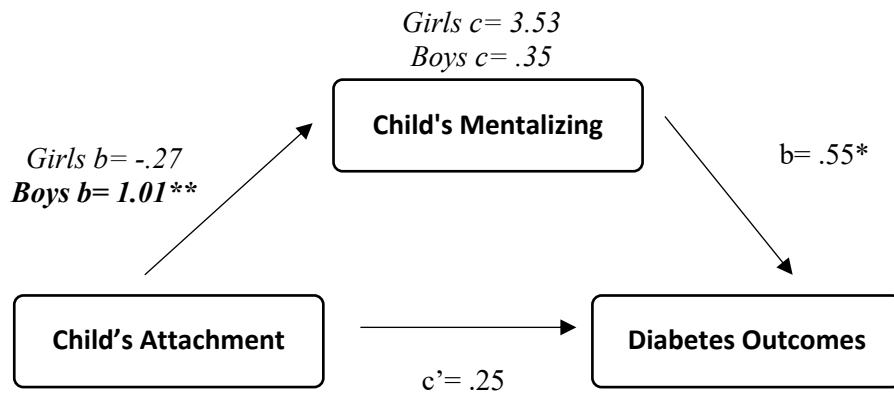


*Mother's stress* did not mediate the relationship between *child's mentalizing* and *diabetes outcomes*, nor did it mediate the relationship between *mother's mentalizing* and *diabetes outcomes*. Similarly, for both boys and girls, *child's stress* did not mediate the relationship between *mother's mentalizing* and *diabetes outcomes*.

### Attachment and Diabetes via Mentalizing

Again, only in boys was a mediation effect found. As shown in Figure 3.2, the indirect effect of *child's attachment* on *child's diabetes outcomes*, through *child's mentalizing*, was positive and significant according to the bootstrap analysis ( $a*b = .23$ ,  $SE = .14$ ) with the 95% CI above zero (.10 to .48). The direct effect of *child's attachment* on *diabetes outcomes* was non-significant. Hence, in boys, secure attachment in boys fosters mentalizing, which in turn leads to better outcomes.

**Figure 3.2. Mediation of Relationship Between Child's Attachment and Diabetes Outcomes Through Child's Mentalizing**



Neither the relationship between *mother's attachment* and *diabetes outcomes* via *mother's mentalizing* and via *child's mentalizing* were significant, nor the relationship between *child's attachment* and *diabetes outcomes* via *child's stress*, for both groups.

### 3.4 Discussion

The present study was designed to investigate the relationships between mother and child mentalizing, mother and child attachment, mother and child stress and child diabetes outcomes. It also aimed to examine whether mother/child stress and mother/child mentalizing mediate the relationships between the present study's independent variables (mother/child attachment, mother/child mentalizing and mother/child stress) and outcome variable (diabetes outcomes), for mother and child separately, as well as in interaction.

The results of this study indicate that, overall, both mother and child mentalizing, attachment and stress appear to have an impact on diabetes outcomes. Furthermore, we found substantial evidence for gender differences in these relationships. In our discussion, we will first consider the role of each of these concepts separately, and then focus on the mediation analyses, and thus the mechanisms that may be involved in explaining diabetes outcomes associated with attachment, mentalizing, and stress in children with diabetes and their mothers.

## **Attachment**

In this study, maternal avoidance attachment was negatively correlated with HbA1c in girls, implying that higher levels of attachment avoidance were associated with better diabetes outcomes, which was unexpected. A possible explanation for this result may lie in the fact that mothers with avoidant attachment strategies are typically experienced by their children to be unavailable (George and Solomon, 2008). While these mothers generally reject their child's attachment needs, they put a strong emphasis on achievement, self-efficacy and task-competent success (Steele and Steele, 2005). As a result, children of avoidant mothers typically have to develop high levels of autonomy and self-reliance very early in life (*Ibid.*, 2005). Moreover, in children with avoidant mothers, high levels of avoidant attachment patterns have been observed (Van Ijzendoorn, 1995).

Because we used the SS in this study (Kerns et al., 2001), which is unable to classify children into specific patterns of attachment, these assumptions remain speculative. Yet, assuming that at least a large proportion of the children of avoidant mothers in this sample also developed avoidant strategies, it is probable

that these children prematurely develop a sense of responsibility that encourages them to take care of their diabetes themselves, so as not to 'bother' their mothers and/or to lose their praise, love, and care. Indeed, in children with avoidant attachment, there tends to be a strong emphasis on achievement, which develops in middle childhood (Mayseless, 2005).

These are the same behaviors that diabetes education, treatment, and management promotes. During diabetic treatment, parents are expected to foster the development of self-care and self-control in their child. Typically, family, medical professionals, and teachers reinforce the child positively when he or she is able to reach good HbA1c levels. Because avoidant children tend to be very sensitive to the expectations of others (*Ibid.*, 2005) diabetes control may become the 'perfect' means for them to satisfy others and or derive love, care, and support. Therefore, these children may achieve a good metabolic control in the short term but, over time, they pay a high cost in terms of psychosocial development and negative health outcomes.

This may be exemplified by the presence of eating disorders (ED) in people with T1D. A 5-year follow-up study (Olmsted, Colton and Daneman, 2008) found that girls with T1D who developed an ED in adolescence presented good metabolic control and treatment compliance in childhood. Indeed, the achievement of good diabetes control includes a rigorous control over food intake and it is known that the dietary restrictions that diabetes imposes are a risk factor for ED in the T1D population (Goebel-Fabbri, 2009). This finding supports the concern that a tendency that is useful for diabetic control in the short term, may share its roots with mental health issues in the long term.

In contrast, in boys, maternal avoidance was associated with negative diabetes outcomes. They presented better diabetes outcomes when they were securely attached to their mothers, while in girls, the security of attachment did not seem to have any implications for their diabetic control, at least not as measured with the SS. A possible explanation for this gender difference, and one that would require much more research, is that boys are more dependent upon their mothers for bodily care. This argument has a socio-cultural context, therefore, the local culture of the sample should be considered, in this case, Chilean.

Anthropological studies have argued that female identity in Chile and Latin America in general, stems from a collective image of women and mothers as homologous. This cultural influence is based on the image of the Virgin Mary (Stevens, 1973; Palma, 1990), which implies the idea of women as strong and suffering mothers who carry the pain of their children and their people (Montecino, 1993). According to the well-known Chilean anthropologist, Montecino (1993) in these cultures, females are attributed to be innately caring and “motherly” (i.e., symbolising protection, care, and love), while men are seen as “filial” (i.e., those who are cared for) (*Ibid.*, 1993). One of the consequences of this kind of identification is the socialization of males as “non-nourishing” (Rapoport, et al. 1977).

This would explain why mothers are prone to delegate self-care to their female children (who are seen to be self-sufficient in this area) while male children are viewed as an object of care, being considered more limited in this area and thus unable to take care of themselves. It may be that males become identified with this image, making it more difficult for them to deal with their bodily care when

their mothers are not available (as in the case of mothers with high levels of avoidance).

If we consider a broader cultural context, it can be argued that in western cultures behaviors linked to self-care and self-control are more highly valued in females than in males. Indeed, one of the most common gender stereotypes is that girls must be clean, neat, well behaved, and should not express aggression. It has even been observed that women who eat less are perceived to be more feminine (Chaiken and Plinner, 1987). These behaviours relate to an attitude whereby biological drives are repressed in order to show that one is “in control”. Therefore, the inherent requirement to be in control in order to manage diabetes successfully would provide more reward to girls than to boys, leading girls to take responsibility for their illness sooner. Indeed, the latter could again be linked to previous findings that females with T1D are at a higher risk than males of developing eating disorders (Nielsen, 2002; Goebel-Fabbri, 2009).

It can therefore be argued that the effect of maternal avoidance could lead girls to be self-efficient in the field of self-care because of its rewarding value, while in boys, because self-care would not be experienced as an achievement, this may not be the case, particularly in more securely attached boys. In more insecurely attached boys, ambivalence in the relationship with their mother could trigger the wish for autonomy, leading to poorer diabetic control.

Nevertheless, more research – and especially longitudinal research – is required to further investigate the role of attachment issues in this population.

## Mentalizing

The maternal reflective functioning scales, *interest and curiosity in mental states* (IC) and *certainty about mental states* (CMS) both correlated negatively with diabetes quality of life dimensions, implying that higher levels of these mentalizing dimensions were related to poorer diabetes outcomes. These results may be explained by considering the findings of Luyten, Mayes, Nijssens and Fonagy (2017). In their study, both IC and CMS were significantly positively correlated with intrusiveness, suggesting that high levels of IC and CMS could be non-adaptive.

In diabetes, it is likely that parents tend to over-focus on their child's changes in mood in order to screen for signals of hyper or hypoglycaemia as a means of prevention. For instance, D'Alberton et al. (2012) reported a common tendency in these parents to over-attribute elements of the illness to their child's emotions, while neglecting other aspects of the child's internal world. As an example, when the child was angry, the parent's first thought was that it related to hyperglycaemia, without considering an alternative interpretation (such as the child may have had a conflict at school). It might well be that, with diabetes, the imperative requirement to interpret the child's signals accurately so as to properly take care of them, generates a need in the mother to assume a vast knowledge of her child's mental states which allows her to feel that she is properly mastering the treatment.

However, besides the dimensions mentioned above, very few other associations between PRF, at least as measured in this study, were found. Study 3 will revisit this issue using observer-rated measures of RF, i.e., the Reflective Functioning Scale (Fonagy, Target, Steele and Steele, 1998) on the Parental



Development Interview (PDI; Aber, Slade, Berger, Bresgi, and Kaplan, 1985; Slade, Aber, Bresgi, Berger and Kaplan, 2004) and the Child Reflective Functioning Scale (CRFS; Ensink, Target and Oandasan, 2013) on the Child Attachment Interview (CAI; Shmueli-Goetz, Target, Fonagy and Datta, 2008; Target, Fonagy, Shmueli-Goetz, Schneider and Datta, 2000).

Regarding children's emotional awareness, in this study, it was found that in boys, the capacity to differentiate and communicate emotions may have a role in the achievement of good diabetes outcomes. These findings are in line with the work of Fonagy and Moran (1989, 1991 and 1993), as reviewed in Chapter 2, in which diabetes outcomes improved as the psychoanalytic treatment progressed. In these studies, it was argued that the improvement was related to the verbalization of psychic conflict, which implies the capacity to recognize and communicate emotions.

However, the above results were only found in boys, which again shows an important gender difference. Similarly, bodily awareness was the only scale of the EAQ that significantly correlated with diabetes in girls. Surprisingly, in boys, this dimension was not significantly correlated with any of the diabetes dimensions.

It could be the case that, in order to achieve good diabetes outcomes, girls need to have a high level of bodily awareness, while this is not necessary for boys. Following the notion outlined above in regard to bodily care dependency, while boys may be more reliant upon their mothers, who are more likely to monitor their bodily signals and their diabetes care in general, in girls the development of these capacities may begin much earlier because of encouragement to be self-sufficient. However, this bodily awareness in girls is not necessarily related to good health

outcomes in the long term; instead, it might be related to anxiety (Ordonez, personal communication, January 18th, 2017) and an earlier than expected adoption of self-care (Fonagy et al., 1987).

Furthermore, in order to achieve good diabetes control, boys may use different emotion regulation strategies than girls. In boys, emotional awareness was higher when diabetes outcomes were better, while girls achieved good diabetes outcomes without showing higher levels of emotional awareness. Again, a good example which supports the latter association can be found with ED, specifically in Anorexia Nervosa (AN) because AN is much more prevalent in females than in males (Nagl et al., 2016) and because diabetes control is related to the control of food intake. In AN, patients present an emotionally deregulated status, but, at the same time, they are in control of their food intake (DeGroot and Rodin, 1998; Fairburn et al., 1995). Similarly, good control of diabetes can be reached at the price of excessive control over food intake, which is useful in the short term but harmful over time (as explained above).

It is clear that the above explanation requires further research in order to be supported; Study 3 focuses specifically on boys in order to test some of the assumptions put forward here. Additionally, it is also necessary to take the above discussion cautiously because the EAQ may only screen certain features of the complex process of bodily awareness, thus more research is needed before any strong conclusions can be drawn.

## **Stress**

Results indicate that in boys, maternal stress has an impact on several dimensions of diabetes outcomes being negatively associated with treatment adherence and quality of life, and positively with diabetes symptoms. As has been discussed earlier in this thesis, the relationship between stress and diabetes outcomes can be bidirectional. Extensive research has shown that diabetes and its concomitant problems are related to stress in parents (Horsch, McManus, Kennedy and Edge, 2007; Landolt et al., 2002; Northam, Anderson, Adler, Werther and Warne, 1996; Streisand et al., 2008). It has also been observed that parental stress is related to negative health outcomes through its role in the genesis of psychosocial problems (Drotar, 1997; Hilliard, Monaghan, Cogen and Streisand, 2011; Kovacs, Goldston, Obrosky and Bonar, 1997).

More specifically, it can be argued that the role of maternal stress in diabetes outcomes is related to the impact of stress on the mother's capacity to mentalize herself and her child. Stress is associated with a switch from a controlled mentalizing to an automatic mentalizing (Fonagy and Luyten, 2009; see Chapter 2). In turn, automatic mentalizing can lead to interpersonal problems, due to the non-reflexive and biased assumptions about the self and others that it implies (Luyten and Fonagy, 2015). Therefore, automatic mentalizing can have an impact on the mother's relationship with her child, impairing the parental task of regulating the child's stress. This difficulty in regulating the child's stress can result in problems in diabetes outcomes, since stress impairs treatment adherence and metabolic control both directly and indirectly, as has been discussed in Chapters 1 and 2.

However, in girls, the opposite occurred: maternal stress was associated with good diabetes outcomes. This surprising result might be explained by the findings of Fonagy, Moran, Lindsay, Kurtz and Brown (1987). In their study on psychological adjustment and diabetes control, they found that in some cases anxiety in children could lead to better diabetes control. They argued that this association could be explained by the fact that anxious children are more efficient in monitoring their blood glucose levels because they are more aware of the signals of hyper or hypoglycaemia in their bodies and so, accordingly, they can act faster. This is also consistent with bodily awareness findings in girls.

Considering the above, it can be argued that in girls, stress results in a strong coping strategy that is successful in the long term but is prone to fail easily, resulting in further physical or mental problems.

## **Mediation Models**

The results of the mediation analysis provided further insight into the relationships between mentalizing, attachment, and stress, especially in boys.

Perhaps the most significant finding from the mediation analyses is that they suggest that mentalizing has a role as an important mechanism in the relationship between attachment and T1D. This might be partly explained by the fact that children with secure attachment have more awareness of their emotions due to the experience of both safety and the encouragement to explore that secure

attachment provides (Bowlby, 1969, 1988; Main et al., 2005). This includes an interest to explore their inner world (Fonagy et al., 2002).

Additionally, the present results suggest that the capacity to recognize and reflect on one's own emotional experience leads to positive diabetes outcomes. This can be explained by the fact that, diabetes care requires a careful observation of bodily signals, including those related to affective experiences, in order to maintain adequate metabolic control. Indeed, the physiological responses triggered by emotions are a known factor of metabolic fluctuations, as was shown in Chapter 1 regarding the endocrinological effect that acute anxiety can have upon BG levels (Lloyd et al., 1999; Wiesli et al., 2005).

Concurrently, it is known that some affective states can be the consequence of a particular BG level. For example, it has been widely shown that patients with T1D experience emotional changes when BG levels are close to either a hypo or hyperglycaemic state (Gonder-Frederick, Cox, Bobbitt and Pennebaker, 1989). It is common that patients report irritability and/or anxiety when experiencing hypoglycaemia (Jordan, 1977), and feelings of frustration and anger when in hyperglycaemia (Clark and Renfert, 1985; O'Connell et al., 1990). Moreover, it has been seen that the patient's rating of subjective emotional states is able to predict glucose levels (Gonder-Frederick, Cox, Bobbitt and Pennebaker, 1989).

Therefore, the capacity to recognize emotions accurately could be the basis of good diabetes control in at least two ways. One example would be, if a patient is able to recognise a current emotion or anticipate that a given situation will trigger a specific emotion that they know will raise their BG levels, then they can make appropriate changes to insulin doses or food intake to prevent a hyper or

hypoglycaemic state. Another example (in the opposite direction), is if a patient is able to identify a forthcoming episode of hypo or hyperglycaemia by experiencing and recognising an affective state which they know will raise/decrease BG levels, they can act to prevent it. Clearly, these actions can lead to metabolic stability and, consequently, good diabetes outcomes. However, the finding that, in boys, bodily awareness was not related with diabetes outcomes, might suggest that emotional recognition may be less focused on the body than presumed.

The second significant mediation model showed that problems with mentalizing in children were negatively related to diabetes outcomes through mother's stress, again this was observed only in boys. This model provides important information regarding the mother-child interactional role (in this case, the effect of a child feature on a mother feature), particularly because mediating models that included the effects of mother's stress on child's mentalizing were not significant. This result would imply that the child's capacity to recognize and reflect on their emotions would affect the mother's perception of her own stress. In this sense, it can be understood that it is the child who sets in motion a series of interactional processes that determine both their own experience and that of their mother.

This explanation echoes the research on evocative person-environment relationships (Scarr and McCartney, 1983). In this respect, several studies have shown the crucial role of child features in eliciting specific parental behaviours (Anderson, Lytton and Romney, 1986; Cunningham and Barkley, 1979; O'Connor, Deater-Deckard, Fulker, Rutter and Plomin, 1998). Something similar can be observed here: it is probable that the child's emotional awareness elicits a sense of

calm in the mother which soothes or avoids stress. It is likely that the mother's perception that her child is mastering the recognition of their own emotions leads her to experience relief, in the sense that, an important auxiliary role that is usually performed by the caregiver (i.e., helping the child understand their feelings) has now been internalized by the child. Thus, the experience of perceiving this form of autonomy in their own child would engender a state of calmness.

This finding also implies that when mothers are less stressed, diabetes outcomes are better. The role of maternal stress on diabetes outcomes - in terms of the interference implied by the caregiver's role in the child's stress regulation - and the role of stress in diabetes outcomes has been discussed above. However, the picture that emerged from the mediation analysis evokes alternative explanations for this association. It is possible that children have better diabetes outcomes when their mothers are less stressed, because mothers are intimately involved in diabetes care, and less maternal stress may mean less family conflict - a known factor related to poorer metabolic control (Grabill et al., 2010; Lewin et al., 2006; see Chapter 1). Nevertheless, a further explanation may lie in a reporting bias; because the PEDSQoL is a parent-report measure, it could be the case that mothers who are less stressed report better diabetes outcomes in their children.

Taken together, both the significant and non-significant mediation models suggest that child-to-parent effects are more important than parent-to-child effects in the caregiver-child dyad. These findings provide valuable insight to the idea that parent-child influences are a highly complex process involving several causal directions. Furthermore, they support the view that a consideration of this complexity is essential when seeking to understand the developmental processes

at work in caregiver-child interactions. Moreover, these results provide some tentative initial evidence that mentalizing is a key aspect on which psychological interventions for diabetic population should focus in order to improve physical and mental health. This issue will be discussed more deeply in Chapter 6.

In sum, the results in this chapter suggest that further research, with an increased focus on reflective functioning in children with Type 1 diabetes, is required.

## **Conclusions**

In this chapter, the results of Study 1 of the current thesis were presented. The study sought to investigate the relationship between attachment, mentalizing and stress in both mothers and children, and the child's diabetes outcomes. It also examined the potential mediational role of stress and mentalizing in the above relationships, in both mothers and children.

It was found that, overall, both mother's and child's mentalizing, attachment and stress appear to have an impact on diabetes outcomes, with essential gender differences.

However, some unexpected findings also emerged. Maternal avoidance and maternal stress were seen to be related to good diabetes outcomes in girls, which was unpredicted. In contrast, in boys, those same maternal features were related to poor diabetes outcomes. Moreover, attachment security and high emotional awareness were also seen to be related to good diabetes outcomes in boys, while in girls these features did not show significant relationships with diabetes



outcomes. Mediation analyses highlighted the key role of reflective functioning in diabetes outcomes in boys, as a possible mechanism through which attachment affects diabetes outcomes.

Overall, this study strengthens the idea that a contemporary attachment approach can be particularly relevant for a comprehensive understanding of Type 1 diabetes in children, establishing an empirical framework for further research on this topic. In the next chapter, we will focus on diabetes specific RF, as this may capture important features of RF in relation to diabetes better than the measures used in this study. In Chapter 5, we will focus on the relationship between mother and child RF in boys specifically, using observer-rated measures of RF.

## **Chapter 4**

### **Diabetes-Specific Reflective Functioning Questionnaire: A Preliminary Validation Study**

#### **Introduction**

This chapter focuses on the development and initial validation of the Diabetes-Specific Reflective Functioning Questionnaire (D-RFQ) in a sample of children aged 8 to 12-years-old (N=97).

Based upon the literature reviewed in chapters 1 and 2, a self-report measure was developed in order to explore the extent to which children with T1D are able to reflect on the psychosocial dimension of their illness.

It is known that reflective functioning (RF) can be measured as a context-specific ability, and that an individual capacity to mentalize can vary regarding the content and object upon which the reflective process is being made (Rudden, Milrod, Target, Ackerman and Graf, 2006; Kullgard, Persson, Moller, Falkenstrom and Holmquist, 2013; Ensink, Berthelot, Bernazzani, Normandin and Fonagy, 2014). It has been argued that measuring symptom-specific RF could give information about how a patient understands the psychological underpinning of his/her illness (Rudden et al., 2009). Indeed, RF for specific symptoms has been measured in several psychological disorders, and studies have demonstrated that the measure of symptom-specific RF can give an account of dimensions that are absent in the assessment of general RF (Rudden et al., 2009).

For example, Kullgard et al. (2013) measured symptom-specific RF in patients with Obsessive Compulsive Disorder. They found that patients who show

high mentalizing regarding general internal states, presented lower mentalizing when they were asked to reflect upon their obsessional symptoms. Rudden et al. (2006) analysed RF in patients with Panic Disorder and their results were similar: patients were less reflective regarding their panic symptoms than about other internal psychological experiences. Ensink et al. (2014) analysed trauma-specific reflective functioning in pregnant women with a history of trauma; similarly, the researchers found that in these women, the trauma-specific RF was much lower than their general RF.

We were prompted therefore to explore the capacity of children with T1D to reflect on the psychological dimension of their medical condition.

However, as highlighted in previous chapters, there have been no previous studies made which addressing whether RF plays a role in T1D and, to our knowledge, no studies have investigated diabetes-specific RF.

In response, we developed the D-RFQ, a brief self-report measure designed to assess diabetes-specific reflective functioning (D-RF), i.e., the ability of individuals to reflect upon the psychological dimension of their diabetes, including the impact of the illness on their mental states and vice versa (-See figure 4.1)

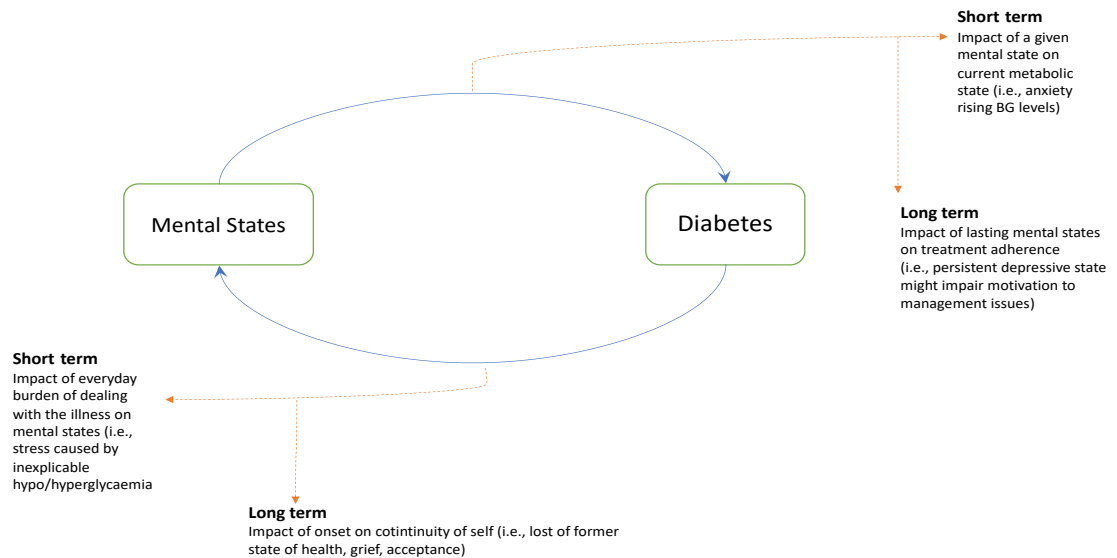


Figure 4.1- Links between Diabetes and Mental States.

Previous studies have linked T1D with several mental health problems. For example, children with T1D are 50% more likely to suffer from a psychiatric disorder than people without the illness (Das-Munshi et al., 2007) and twice as likely as their healthy peers to suffer from depression (Anderson et al., 2001; for further examples see chapter 1). Across the previous chapters, it has been argued that the relationship between diabetes and psychopathology is bi-directional; on the one hand, diabetes has an impact on the individual's psychosocial functioning, and on the other hand, the psychosocial functioning of individuals affects the course of the illness. However, the mechanisms by which T1D and psychosocial functioning are associated have not been established. The measure presented here represents a first attempt to observe this association, by exploring the effect of a diabetes-specific RF on attachment, psychopathology and stress.

The aims of this study, therefore, were threefold. First, to investigate the factor structure of the D-RFQ using Principal Component Analysis (PCA); second, to investigate the internal consistency of the measure; and third, to explore relationships among the D-RFQ and general RF (Emotional Awareness Questionnaire), attachment (Security Scale), stress (Stress in Children), psychopathology (Brief Problem Monitor), and diabetes outcomes (Pediatric Diabetes-Specific Quality of Life and HbA1c).

In line with the model outlined above, it was initially expected that a one-factor structure would emerge with items capturing one general dimension of D-RF. Secondly, it was expected for this factor to be internally consistent. Finally, theoretically meaningful correlations between the D-RFQ and measures of related constructs were expected. The D-RFQ items were largely formulated to gauge an individual's ability to mentalize diabetes, through questions such as, *"When I feel sad, nervous, angry or excited, I think that these emotions may influence my glucose levels."* Our initial expectation was that higher levels of D-RF would reflect a greater degree of functional mentalizing about diabetes, which in turn could be linked to improved health outcomes, as argued throughout this thesis.

Specifically, we expected to find: 1) a positive correlation between the D-RFQ and general RF, 2) a positive correlation between D-RF and security of attachment, 3) a negative correlation between the D-RFQ and stress, 4) a negative correlation between the D-RFQ and psychopathology, 5) positive correlations between the D-RFQ and diabetes-specific quality of life, and finally, 6) a negative correlation between D-RF and HbA1c.

In the following pages, a summary of the main findings of Study 2 will be presented and critically discussed.

## **4.1 Methods**

### **4.1.1 Participants and Procedures**

Children in Study 2 were recruited using the same process described for Study 1 and a large part of the present sample contains the sample from the earlier study.

As mentioned in chapter 3, an invitation letter containing the study details was sent by E-mail to the families of all the children listed in the database aged between 8 and 12-years-old who had been diagnosed with the condition for more than 6 months. Mothers who expressed an interest in participating received a second E-mail with a link to a specially-designed webpage containing the study's information sheets and consent forms (see Appendix A). In total, 97 children (8 to 12-years-old) completed a package of questionnaires (see below). Detailed information about the sample characteristics can be found in the results section of the present chapter.

The present study was approved by the UCL Research Ethics Committee, Number 8899/001 (See Appendix B)

### **4.1.2 Measures**

**D-RFQ.** The development of the D-RFQ proceeded in four stages. In the first stage, items were generated based on a careful screening of the relevant literature on reflective functioning (RF), and the literature on both general psychosocial and

specifically psychodynamic perspectives on diabetes, as presented in chapters 1 and 2. In addition, items were formulated based on descriptions and examples in the Child Reflective Functioning Scale (Ensink, Target and Oandasan, 2013; Ensink, Normandin, Target, Fonagy, Sabourin and Berthelot, 2015), which measures reflective functioning during middle childhood as elicited in response to the Child Attachment Interview (CAI; Shmueli-Goetz et al., 2008; Target, Fonagy, Shmueli-Goetz, Datta, and Schneider, 2000).

First, a pool of 20 items was developed. All items were scored on a positive scale, except items 6 (*I know exactly what other people think about me because I have diabetes*) and 2 (*My glucose levels depend only on what I eat and how much exercise I do*), which were reverse scored. Overall, higher scores were considered to reflect higher D-RF. Second, an expert in the field of mentalizing was asked to choose the 10 items that best reflected the concept of RF in diabetes, with the consideration that this was a reasonable number of items for a middle-childhood questionnaire. Moreover, the expert was asked to provide additional comments and suggestions concerning the item wording. Using these ratings, the 10 remaining items formed the basis of the D-RFQ. Items had to be completed using a 5-point Likert-type scale with an anchor format adequate for children (Chambers and Johnston, 2002) using levels of similarities to self (e.g., *not like me at all* to *very much like me*). Third, the questionnaire was “forward translated” (WHO Guideline, 2017) into Spanish by the first author (SC) and then “back-translated” (*Ibid.*, 2017) by an English native speaker. Finally, a small pilot study was conducted before the actual study. The questionnaire was administered to 10 children between 8 to 12-years-old

in order to test children's understanding of the questions. After the pilot study, minor changes in wording were made (for the complete set of items, see Appendix D).

**Emotional Awareness Questionnaire (EAQ-30; Rieffe et al., 2008).** General RF was measured with the Latin-American version (Ordóñez, Prado-Gascó, Villanueva and González, 2016) of the EAQ (EAQ-30; Rieffe et al., 2008), which was used as a proxy for mentalizing in children. The EAQ-30 has been designed for children from 8-years-old and has 30 items, measuring six features of emotional awareness: (1) differentiation of emotions (DE) (i.e., the ability to differentiate between emotions and locate their antecedents; item sample: "It is difficult to know whether I feel sad, or angry, or something else"); (2) verbal sharing (VS) (i.e., the capacity to communicate emotions; item sample: "I find it hard to talk to anyone about how I feel"); (3) not hiding emotions (NE) (i.e., the tendency not to keep one's emotional experiences hidden from others; item sample: "Other people don't need to know how I am feeling"); (4) bodily awareness (BA) (attention to the physiological aspects of the emotional experience and awareness that emotions are accompanied by bodily symptoms; item sample: "When I feel upset, I can also feel it in my body"); (5) attending to other people's emotions (OTE; item sample: "It is important to know how my friends are feeling"); and, (6) analysis of own emotions (OWE; item sample: "When I am angry or upset, I try to understand why"). Responses are rated on a 3-point scale (1 = never, 2 = sometimes, 3 = often). Reliability was established from two different age group samples, primary and secondary school ages and the Cronbach's alpha for each scale on both samples were established as follows: Differentiation of emotions: .67, .74; Verbal sharing: .68, .77; Not hiding: .68, .76;



Bodily awareness: .64, .74; Others' emotions: .65, .77; Own emotions: .65, .77. In the present study, Cronbach's alpha for the EAQ subscales were as follows: DE  $\alpha=.71$ ; VS  $\alpha=.71$ ; NH  $\alpha=.74$ ; BA  $\alpha=.70$ ; OtE  $\alpha=.74$ ; OwE  $\alpha=.74$ .

**The Security Scale (SS; Kerns et al., 1996).** Attachment security was assessed using the Latin-American version (Cárdenas-Fernández, in press) of the SS (Kerns et al., 1996): a 15-item questionnaire that assesses a child's perception of attachment security in relation to their mother. Each item presents a forced choice (Harter, 1982) between two statements whereby the subject rates 'sort of true for me' or 'really true for me'. Items are scored from 1 to 4, with a higher score indicating greater perception of security. The SS was designed specifically for middle childhood and early adolescence, and items assess the following: (1) the degree to which children believe a particular attachment figure (the mother in this case) is responsive and available; (2) the child's tendency to rely on the attachment figure in times of stress; and, (3) ease and interest in communicating with the attachment figure as reported by the child. Its reliability has been proved to be high. In validation studies, the SS demonstrated high test-retest stability ( $r=.75$ ; 14 days) and Cronbach alpha's range from .84 to .88 in two studies with 10 to 12-year-old children who also participated in a follow-up study 2 years later (Kerns et al., 2000) and completed projective measures of attachment, such as the Separation Anxiety Test (SAT; Resnick, 1993). Both ratings and classifications on the SAT were related with SS scores (e.g., children reporting greater security to their mother in the SS were less dismissive and had more coherent discourse during the SAT interview). The SS Cronbach's alpha for the present study was  $\alpha=.78$ .

**Stress in Children (SiC) (Osika et al., 2007).** Stress was measured using the Chilean version (Caqueo-Urizar, Urzúa & Osika, 2014) of the SiC (Osika et al., 2007). This is a 21-item questionnaire for school-age children designed to assess perceived distress, levels of well-being and aspects of coping and social support. Participants are asked to rate how often they felt or thought in a certain way during the last month, ranging from *never* to *very often* with higher scores meaning higher levels of stress. The SiC demonstrates high internal consistency with a Cronbach's alpha-coefficient of .79 for the complete test score and .79, .67 and .62 for the three subscales (lack of well-being (LWB), distress (D) and lack of social support (LSS), respectively). The SiC showed to be reliable in the Chilean population for the three subscales, (LWB, D and LSS) with a Cronbach's alpha-coefficient of .80; .77 and .69 respectively (Caqueo-Urizar et al., 2014). The SiC Cronbach's alpha for the present study were: LWB  $\alpha$ =.73; D  $\alpha$ =.69; LSS  $\alpha$ =.71.

**Brief Problem Monitoring.** General psychopathology was assessed using the Spanish version (Penelo, de la Osa, Navarro, Domenech and Ezpeleta, 2017) of the BPM for ages 6 to 18 (BPM; Achenbach et al., 2011): a rating instrument for monitoring children's psychosocial functioning. Items are drawn from the Child Behaviour Checklist for ages 6 to 18 (Achenbach & Rescorla, 2001). Each item is rated 0 = 'not true', 1 = 'somewhat true', or 2 = 'very true'. The BPM includes items for rating internalising (INT), attention (ATT) and externalising problems (EXT). The BPM-P has shown high test-retest reliability and internal consistency (TOT  $r$ =.85

$\alpha=.92$ ; INT  $r=.81$   $\alpha=.80$ ; ATT  $r=.83$   $\alpha=.85$ ; EXT  $r=.83$   $\alpha=.85$ ). This study presented the following Cronbach's alpha on this scale: INT:  $\alpha=.80$ ; ATT:  $\alpha=.75$  and EXT:  $\alpha=.83$ .

**Glycosylated Haemoglobin (HbA1c) and Paediatric Quality of Life Inventory Diabetes Module 3.2 Parent-Report (PEDSQoL 3.2 Diabetes Module; Varni et al., 1999).** Diabetes outcomes were assessed with two measures: HbA1c exams (see chapter 3) and the Chilean version (Varni, 2003) of the diabetes-specific PEDSQoL (Varni et al., 2003). This scale measures the child's parent-reported diabetes-specific quality of life. It assesses how well the illness has been integrated in the child's life and concerns several dimensions of diabetes care, which are reflected on the subscale. In this sense, the PEDSQoL can be considered an indicator of diabetes outcomes. It consists of 28 items divided into four subscales: (1) Diabetes symptoms (11 items), (2) Treatment adherence (11 items), (3) Diabetes concerns (3 items; e.g., in the last month, "it has been a problem for my child being worried about future diabetes complications" ), and (4) Diabetes communication (3 items; e.g., in the last month, "it has been a problem for my child to explain his illness to other people"). Responses are on a 5-point Likert scale (ranging from *never a problem* to *almost always a problem*, with higher scores meaning fewer problems (therefore, higher Diabetes-Specific Quality of Life). Most scales in this measure exceeded the reliability standard of .70, with  $\alpha$ -coefficients for each subscale, as follows: Diabetes symptoms (DS): .81; Treatment barriers (TB): .68; Treatment adherence (TA): .68; Worry (W): 0.81; Communication (C): .84. In the present study, Cronbach's alpha on the PEDSQoL were: DS:  $\alpha=.81$ ; TA:  $\alpha=.73$ ; DCC:  $\alpha=.85$  and DCM:  $\alpha=.80$

## **4.2 Data Analysis**

To explore the factor structure of the D-RFQ, PCA with varimax was implemented. The criteria used to define factors were as following: (1) the number of components with an eigenvalue below 1, (2) the Scree Test, and (3) interpretability. Next, internal consistency was tested using Cronbach's alpha. Relationships between D-RFQ, demographic features, emotional awareness, diabetes-specific quality of life, attachment, stress and psychopathology were investigated using Pearson correlation. SPSS 24.0 was used for all analyses.

## **4.3 Results**

### **4.3.1 Demographic Features**

Children in this sample were 10 years old on average ( $SD=1.54$ ). Sex was roughly equally divided, with 51 boys (52.6%) and 46 girls (47.4%). Glycosylated Haemoglobin levels were on average 8.5%, reflecting a normal-to-good diabetic control in the sample. Similar to Study 1, the range of HbA1c in the sample was small, with an SD of 1.3 (see Table 4.1 below)

**Table 4.1 Children Demographic Information**

<b>Items</b>	<i>Mean (SD) or (%)</i>	<i>n</i>
<b>Age (Years)</b>	10 (1.54)	97
<b>Gender</b>		
<i>Male</i>	52.6%	51
<i>Female</i>	47.4%	46
<b>Socioeconomic Level of parents (%)</b>		
<i>High</i>	31%	30
<i>Middle</i>	47.4%	46
<i>Low Middle</i>	14.4%	14
<i>Poverty</i>	7.2%	7
<b>Glycosilated Haemoglobin (HbA1c %)</b>	8.5 %(1.3)	91

#### 4.3.2 Principal Component Analysis

Before performing PCA, the matrix with inter-item correlations was scanned, showing that four items (items 2, 5, 6, 10) had no significant correlation with any of the others (see Table 4.2). Thus, firstly, these items were removed. The overall Kaiser-Meyer-Olkin (KMO) measure was .62 with individual KMO measures all greater than .60, which are significant according to Kaiser (1974). Bartlett's Test of Sphericity was also statistically significant ( $p < .0005$ ), indicating factorability in the data, and thus, the adequacy of the data to be analysed with PCA (see Tables 4.3 and 4.4).

A PCA subsequently revealed two components that had eigenvalues greater than 1 and which explained 26.3% and 24.6% of the total variance (see Table 4.5). However, visual inspection of the Scree Plot (see Table 4.6) indicated that only one component should be retained (Cattell, 1966). In addition, a one-component solution

met the interpretability criterion, as the second factor in the two-factors solution were difficult to interpret. Hence, one component was retained. The one-component solution explained 33% of the total variance. Component loadings and communalities of the one factor solution are presented in Table 4.7.

**Table 4.2 Correlation Matrix**

<b>D-RFQ Items</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<i>1. Since I have had diabetes, I have felt emotions that I had never felt before.</i>	1.0	-.04	.17	.23	-.02	.18	.10	.11	.12	.10
<i>2. My glucose levels depend only on what I eat and how much exercise I do.</i>	-.04	1.0	.13	-.14	.08	.07	-.12	-.15	-.03	-.06
<i>3. I don't know what other people think about my diabetes.</i>	.17	.13	1.0	.21	.06	-.14	.13	.09	.29	.01
<i>4. I think that it is normal to sometimes feel angry about having diabetes.</i>	.23	-.14	.21	1.0	.12	.08	.40	.13	.27	.24
<i>5. Sometimes I imagine how it will be like living with diabetes when I get older.</i>	-.02	.08	.06	.12	1.0	.03	-.06	.07	.08	-.09
<i>6. I know exactly what other people think about me because I have diabetes.</i>	.18	.07	-.14	.08	.03	1.0	.08	-.05	-.09	-.00
<i>7. Sometimes I feel sad or angry because I have diabetes and I just want to stop taking care of it.</i>	.10	-.12	.13	.40	-.06	.08	1.0	.37	.14	.06
<i>8. Since I have had diabetes, the relationship with my mother has changed.</i>	.11	-.15	.09	.13	.07	-.05	.37	1.0	.11	.01
<i>9. It is very difficult for me to talk about my diabetes with friends that have no diabetes.</i>	.12	-.03	.29	.27	.08	-.09	.14	.11	1.0	.05
<i>10. When I feel sad, nervous, angry or excited, I think that these emotions may influence my glucose levels.</i>	.10	-.06	.01	.24	-.09	-.00	.06	.01	.05	1.0

Note: \*p < .05, \*\* p < .01.

**Table 4.3 Individual KMO Measures of Sampling Adequacy**

<b>Kaiser-Meyer-Olkin Measures</b>	
1. <i>Since I have had diabetes, I have felt emotions that I have never felt before.</i>	.67
3. <i>I don't know what other people think about my diabetes.</i>	.68
4. <i>I think that it is normal to sometimes feel angry about having diabetes.</i>	.63
7. <i>Sometimes I feel sad or angry because I have diabetes and I just want to stop taking care of it.</i>	.60
8. <i>Since I have had diabetes, the relationship with my mother has changed.</i>	.60
9. <i>It is very difficult for me to talk about my diabetes with friends that have no diabetes.</i>	.66

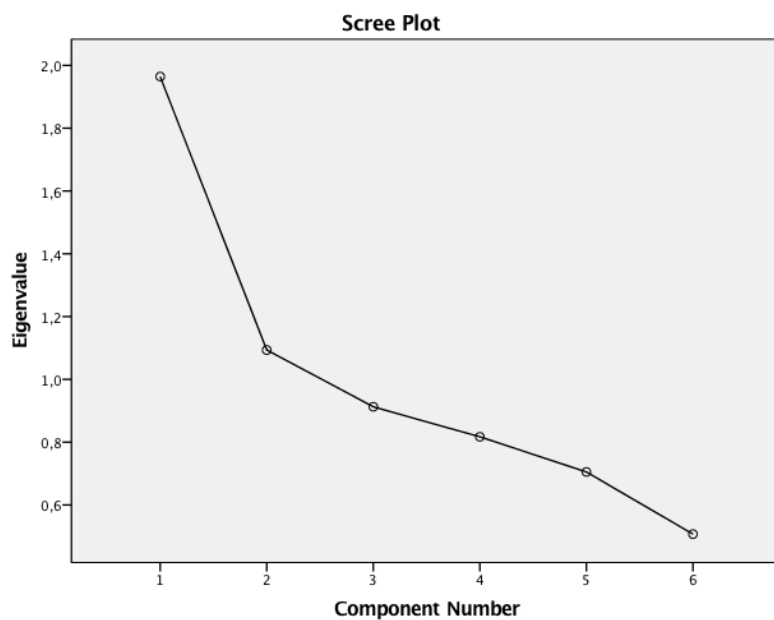
**Table 4.4 KMO Measure of Sampling Adequacy and Bartlett's Test of Sphericity**

<b>Kaiser-Meyer-Olkin Measure</b>		.63
<b>Bartlett's test</b>	<i>Aprox. Chi- Square</i>	47.99
	<i>df</i>	15
	<i>Sig.</i>	.000

**Table 4.5 Total Variance Explained**

Component		1	2	3	4	5	6
<b>Initial Eigenvalues</b>	<i>Total</i>	1.96	1.09	.913	.82	.71	.51
	<i>% of Variance</i>	32.74	18.23	15.21	13.62	11.75	8.45
	<i>Cumulative %</i>	32.74	15.21	66.18	79.80	91.55	100
<b>Rotation Sums of Squared Loadings</b>	<i>Total</i>	1.58	1,47				
	<i>% of Variance</i>	26.32	24,6				
	<i>Cumulative %</i>	26.32	50,96				

**Table 4.6 Scree Plot**





**Table 4.7 Loadings and Communalities One Factor Solution**

<b>D-RFQ Items</b>	<b>Loadings</b>	<b>Communalities</b>
<i>4. I think that it is normal to sometimes feel angry about having diabetes.</i>	.68	.47
<i>7. Sometimes I feel sad or angry because I have diabetes and I just want to stop taking care of it.</i>	.67	.44
<i>9. It is very difficult for me to talk about my diabetes with friends that have no diabetes.</i>	.56	.31
<i>3. I don't know what other people think about my diabetes.</i>	.52	.27
<i>8. Since I have had diabetes, the relationship with my mother has changed.</i>	.52	.28
<i>1. Since I have had diabetes, I have felt emotions that I have never felt before.</i>	.45	.20

Note: Extraction Method: Principal Component Analysis

#### **4.3.3 Internal Consistency**

The 6-item scale had a level of internal consistency of .58 for the total sample, .49 in girls and .63 in boys, which is below common acceptable standards, particularly in girls.

#### 4.3.4 Correlational Analyses

##### Correlations with Demographic Features

Correlations with demographic features were non-significant (see Table 4.8)

**Table 4.8 Correlations with Demographic Information**

Demographics features	D-RFQ All	D-RFQ Girls	D-RFQ Boys
<i>Mother's Education</i>	-.07	-.165	-.097
<i>Socioeconomic Level</i>	.06	.049	.054
<i>Mother's Age</i>	-.07	-.071	-.077
<i>Child's Age</i>	-.00	-.072	-.004

Note:\*  $p < .05$ , \*\*  $p < .01$ .

##### Correlations with Emotional Awareness, Attachment, Stress and Psychopathology

Contrary to expectations, D-RF was highly negatively correlated with the EAQ overall score [ $r = -.48$   $p < .001$  (all);  $r = -.50$  (boys)  $p < .001$ ;  $r = -.48$   $p < .005$  (girls)]. When looking at the subscales, D-RF was negatively correlated with *differentiation of emotions* [ $r = -.33$   $p < .005$  (all);  $r = -.34$  (boys)  $p < .005$ ;  $r = -.31$   $p < .005$  (girls)], *verbal sharing of emotions* [ $r = -.46$   $p < .001$  (all);  $r = -.40$  (boys)  $p < .001$ ;  $r = -.50$   $p < .001$  (girls)] and *not hiding emotions* [ $r = -.31$   $p < .001$  (all);  $r = -.45$  (boys)  $p < .001$ ]. D-RF did not correlate significantly with *bodily awareness*, nor with *analysis of own emotions* and *attending to other people's emotions*.

Also, unexpectedly, D-RF and attachment were negatively correlated [ $r = -.34$   $p < .005$  (all);  $r = -.30$  (boys)  $p < .001$ ;  $r = -.38$   $p < .005$  (girls)]. Additionally, D-RF and

stress were positively correlated in the total sample and in boys [ $r = .29$   $p < .005$  (all);  $r = .32$  (boys)  $p < .005$ ].

Regarding psychopathological symptoms, D-RF showed a positive correlation with *internalizing symptoms* for the total sample and boys, but not girls [ $r = .32$   $p < .001$  (all);  $r = .49$  (boys)  $p < .001$ ]. No significant correlation was found between D-RF and both *externalizing* and *attentional* problems (see Table 4.9 for all the described correlations).

**Table 4.9 Correlation D-RFQ between EAQ, SS, SIC, and BPM**

Scale		D-RFQ All	D-RFQ Boys	D-RFQ Girls
<b>EAQ Dimensions</b>	<i>Differentiation of emotions</i>	-.33*	-.34*	-.31*
	<i>Verbal sharing of emotions</i>	-.46**	-.40**	-.50**
	<i>Not hiding emotions</i>	-.31**	-.45**	-.06
	<i>Bodily awareness</i>	-.11	-.13	-.06
	<i>Attending to other people emotions</i>	-.10	-.15	-.05
	<i>Analysis of own emotions</i>	-.15	-.15	-.10
	<i>Total</i>	-.48**	-.50**	-.38*
<b>Security Scale</b>		-.34*	-.30**	-.38*
<b>SIC Dimensions</b>	<i>Lack of social support</i>	.20*	.25*	.16
	<i>Distress</i>	.31**	.27*	.33*
	<i>Lack of well-being</i>	.21*	.29*	.11
	<i>Total</i>	.29*	.32*	.25
<b>BPM Dimensions</b>	<i>Internalizing symptoms</i>	.32**	.49**	.09
	<i>Attentional problems</i>	.04	.23	-.24
	<i>Externalizing problems</i>	.12	.20	-.03

Note: \*  $p < 0.05$ , \*\*  $p < 0.01$ .

## Correlations with Diabetes Outcomes

Unexpectedly, higher levels of D-RF correlated with higher levels of *diabetes symptoms* [ $r = -.21$   $p < .005$  (all);  $r = -.31$  (boys)  $p < .005$ ], *treatment adherence* [ $r = -.24$   $p < .005$  (all);  $r = -.44$  (boys)  $p < .001$ ], *diabetes communication* [ $r = -.21$   $p < .005$  (all);  $r = -.29$  (boys)  $p < .005$ ] and total score [ $r = -.26$   $p < .005$  (all);  $r = -.41$  (boys)  $p < .001$ ]. All the above-mentioned correlations were found to be significant only in boys. No significant correlation was found between D-RF and *diabetes concerns* nor Hba1c (correlations are detailed in Table 4.10).

**Table 4.10 Correlation Between D-RFQ and Diabetes (PEDSQoL and Hba1c)**

		D-RFQ All	D-RFQ Boys	D-RFQ Girls
<b>PEDSQoL Dimensions</b>	<i>Symptoms</i>	-.21*	-.31*	.03
	<i>Treatment Adherence</i>	-.24*	-.44**	.14
	<i>Concerns</i>	-.14	-.19	-.02
	<i>Communication</i>	-.21*	-.29*	-.10
	<i>Total</i>	-.26*	-.41**	.04
<b>Hba1c</b>		.20	.13	.30

Note: \*  $p < 0.05$ , \*\*  $p < 0.01$

#### **4.4 Discussion**

An initial objective of this study was to explore the factor structure and internal consistency of the D-RFQ, a brief self-report measure designed to assess diabetes-specific reflective functioning (D-RF), i.e., the ability to reflect upon diabetes and its impact on one's internal psychological world. We also aimed to test relationships between the D-RFQ and general RF, attachment, psychopathology, stress and diabetes outcomes. Broadly speaking, the D-RFQ was shown to have one underlying factor, which was expected. However its associations with other measures were mostly unexpected. We discuss these results in detail below.

Before conducting the PCA, four items (2, 5, 6, and 10) showing no significant inter-item correlation were deleted from the original pool. Our methodological justification was that non-correlating items were likely to be measuring different phenomenon, distant from D-RF, and would not therefore contribute to the assessment of the construct of interest (Cohen and Swerdlik, 2005). Removing such items also helped to maintain homogeneity (i.e. the extent to which items in a scale are unifactorial) (Cohen and Swerdlik, 2005).

It should be noted that the items removed included the only two (2 and 6) which were negatively formulated (i.e, where higher scores reflected lower RF) and therefore worded differently. It is possible that this presentational disparity was significant, invoking a different set of psychological phenomena to the one we set out to measure. Further analysis of how the wording and theoretical basis of specific items relates to the construct under investigation should be considered in future studies.

It would also be beneficial to conduct a further process of content validity to exclude irrelevant content from the scale. For example, an explorative qualitative study, interviewing children with T1D to dig deeper into their reflections and conceptualizations of T1D, would increase our understanding of the construct of D-RF and help with the development of relevant items.

The factor analysis was conducted on the remaining items. This suggested that one theoretically significant factor underlies the D-RFQ items. Also, the scale showed to be independent of demographic features. Regarding internal consistency, in girls, the scale was shown to be not reliable and in boys, the coefficient alpha was below commonly accepted standards (i.e., .70), with a Cronbach's alpha of .63. However, according to Kline (2013), an alpha just below .7 could be acceptable when measuring psychological constructs.

Therefore, our discussion of results will focus on boys only.

The validation of the D-RF scale obviously needs further research. However, our findings (most of them unexpected) can be discussed from several perspectives.

First, it might be that the D-RFQ does not properly capture reflective functioning about diabetes. Because we cannot be sure regarding this point with our current results, further studies are needed into the implications and boundaries of the construct of D-RF (content validity mentioned above) and its relationship with other forms of reflective functioning (criterion-related validity).

Second, it might be that the scoring of the scale was planned such that high scores would reflect high reflective functioning, but, it might be that some items should have been designed to reflect high reflective functioning in the middle of the scale.

Third, we could hypothesise that the results of the present study suggest the dimension assessed in the D-RFQ could be related to a form of reflectivity in diabetes that is problematic for the patient. High scores on the scale would thus correlate with high psychopathology, high stress, low attachment security, low emotional awareness and low diabetes-specific quality of life.

In line with this, we might hypothesise that higher scores in the D-RF reflect a phenomenon close to that defined by the “hypermentalizing” construct. If that is the case, we could consider how hypermentalizing manifests itself in diabetes, taking our results as a starting point.

### **Hypermentalizing in diabetes hypothesis**

Hypermentalizing (HM), or pseudomentalizing (PM), (Sharp, Pane, Ha, Venta, Patel and Sturek, 2011) is the tendency to generate inaccurate representations of mental states that *prima facie* appear as reflective, but they lack essential aspects of being reflective: they neither recognize the opaqueness of mental states nor are supported in reality (Sharp et al., 2011)

Therefore, they constitute a distorted mentalizing, which has been associated with elevated levels of psychopathology (Sharp et al., 2011; Sharp and Fonagy, 2008). For example, patients with Borderline Personality Disorders (BPD) have shown to be highly successful in recognizing mental states in others, with a particular sensitivity for non-verbal cues (Frank and Hofmann 1986; cited in Fonagy et al., 2017). Although this could be considered a high mentalizing ability, in BPD it is marked by an over-certainty about mental states that reflects a lack of awareness about the opacity of mental states. Mentalizing in BPD patients is typically highly

emotionally-driven, leading to a rigid model of other's minds, with a level of confidence in their interpretation that lacks the doubt needed to reflect - doubt that would be present in more cognitive-driven mentalizing (Baron-Cohen et al., 2008). Therefore, in BPD there is a clear imbalance between the emotional and cognitive dimension of mentalizing (see chapter 2).

Moreover, in BPD implicit mentalizing is not counterbalanced by explicit mentalizing (Fonagy and Luyten, 2009). Similarly, an HM tendency has been found in individuals with anorexia nervosa, as they express high levels of reflectivity that is overly focused on the self, with a severely distorted model of the self, marked by harsh self-judgment in particular (Bers, Blatt and Dolinsky, 2004).

We might hypothesise that the results of the present study reveal a tendency close to PM or HM, which is specific to diabetes.

In the hypothetical case of HM in diabetes, this would take the form of a rigid model of the illness in terms of mental states, one that is disconnected from reality and therefore closed to new information.

In the case of high D-RF, such a model might exclude awareness of the real threats that the illness presents (such as potential complications). It would be as if the patient is saying, "I know everything about my diabetes and I am fine with my diabetes; I do not think it is a big issue", reflecting an overly cognitive type of mentalizing.

Hence, this would imply a distorted version of what the subject is genuinely experiencing on a subjective level regarding diabetes, not taking into account the affective dimension of diabetes. The presence of this rigid and non-reflective model



of the self would also explain the positive correlation between D-RF and stress as such individuals lack genuine mentalizing and thus the capacity for affect regulation.

In contrast, a more realistic and flexible model of diabetes in relation to the self would allow the inclusion of alternative perspectives and a more optimistic view to emerge. In this case, the patient could say, for example, “I know diabetes is a big issue, I feel a bit distressed sometimes about it, but I realize that I am able to handle it because my family and doctors are helping me.” That is to say, the recognition of the proper threat would allow the patient to acknowledge both negative and positive aspects in a more integrated manner.

Accordingly, PM or HM with regard to diabetes might show an over-focus on diabetes and its aspects, a kind of “tunnel vision” in which the illness takes all the available mental space. This over-focus would involve an inability to disengage, which is necessary to inhibit the stress response that arises due to the threat represented by the illness. This process has been called “interference inhibition” in the Kalisch, Muller, and Tuscheer (2015) theory of resilience known as PASTOR (Positive Appraisal Style Theory of Resilience).

Kalisch et al argue that all resilience factors have one central mechanism in common: the presence of a positive appraisal style. Therefore, the way in which individuals appraise, assess, and interpret a given event that is potentially threatening, will determine their emotional and behavioural response. However, for a positive appraisal to emerge, different processes would be activated depending on the level of threat the event represents. The first process (PASTOR claim 1) is called “Positive Classification” and consists of the automatic classification of an event as positive. In this case, the event is positively appraised and, consequently, the stress

response is prevented. However, if the event is threatening enough (such as the onset of a chronic illness like diabetes), to activate an automatic negative appraisal, the stress response would be activated, and for a positive appraisal to emerge, a second process would be activated. This process is called "Positive Re-Appraisal" (PASTOR claim 2) and leads to an attenuation of the stress response. The positive re-appraisal is related to a new assessment of an old event, in an effort to change the negative value into a positive one, in order to regulate the stress response. However, for the re-appraisal to be positive, further cognitive mechanisms will be needed so as to counteract the interference of other negative appraisals emerging simultaneously and competing with the positive ones. This mechanism is the PASTOR claim 3 and is called "interference inhibition," the capacity to inhibit the negative appraisal.

Taking Kalisch et al.'s (2015) theory into account, high D-RF, as assessed by the D-RFQ, could be interpreted as a HM tendency reflecting an over-focus on diabetes and/or a distorted representation of its implications that impairs the process of interference inhibition, thus undermining resilience. Patients with high D-RF would fail in the a positive appraisal process due to their inability to disengage from the re-traumatizing triggers that their distorted mental representation of the illness would continually encounter. This tendency would result in a limitation of resilience, leaving them vulnerable to psychopathology, as reflected in the present results. The lack of resilience is related to the emergence of psychopathology; Indeed, resilience has been understood as the "mental immune system" (Luyten, Boddez, and Hermans, 2015; Boden and McLeod, 2015).

This limitation of resilience and the concomitant failures in mentalizing would explain the positive correlations between D-RF and both stress and psychopathology. These results are consistent with previous work linking mentalizing impairments and limitations of resilience in light of the PASTOR theory, specifically in the observation of BPD patients (Fonagy, Luyten, Allison and Campbell, 2017). Fonagy and colleagues have argued that patients with BPD have problems with the process of positive re-appraisal (PASTOR claim 2) because they are unable to re-learn how to mentalize a situation in a different way (Fonagy et al., 2017). Difficulties in re-evaluating a situation would lead these patients to become wedged in their misinterpretations. The fact that they attribute mental states to behaviours in a rigid way (as mentioned above), does not allow re-interpretation, leading to a limitation of resilience and, in turn, to a non-regulated stress response.

Similarly, in the present study, patients with a greater focus on diabetes presented higher levels of stress and psychopathology. Thus, it could be argued that a hyper-reflectivity upon diabetes might be maladaptive. This is because it would imply being in contact with re-traumatizing triggers, which would impair the mechanism of Positive Appraisal Style, leading to inadequate regulation of the stress response.

However, as mentioned already, these are speculations, given that the present study has several limitations, which are addressed below.

First, the sample size may be too small for factor analysis, and it lacks variability concerning diabetes outcomes. Moreover, it may be that participants in the current sample presented some reporting bias that would be important to avoid in further studies. This bias is grounded in the fact that a large number of participants

were attendees at activities organised by the Diabetes Foundation. In consequence, they were committed to learning about diabetes and had received diabetes psychoeducation. They may already have had awareness of which emotions they were supposed to feel regarding diabetes, but in a “rote learning” form, not necessarily linked with reflectivity. Therefore, future research should consider the careful distinction between knowledge, psychoeducation about the illness, and RF to deal with this issue. This is linked to the need for a more in-depth content validity process, mentioned at the beginning of this discussion.

Recruiting participants that are more widely representative of the population of children with diabetes would be also highly recommended.

Second, test-retest reliability should be investigated, and prospective research is needed to investigate the potential causal role of D-RF.

Third, it would be interesting to compare this self-report measure with an observer-rated tool assessing similar constructs in order to test the strengths and weaknesses of the self-report nature of the measure.

Finally, this study only focused on the relationship between the D-RF and child features. In regard to the aims of the present thesis, it would have been highly interesting and informative to have developed a Parental Diabetes-Specific Reflective Functioning Scale (P-DRFS). This study is currently underway.

In conclusion, the D-RFQ preliminary validation reflects that one factor underlies the scale and this showed to be relatively internally consistent in boys, but not in girls. Results were unexpected and suggest a hypothesis to be tested: that D-RFQ measures a phenomenon akin to that of hypermentalizing (HM), characterized by an over-focus on diabetes. Hence, HM in diabetes may be associated with

negative mental health outcomes because, as a distorted form of mentalizing, it does not fulfill a stress regulating function, and because it also affects the emergence of a positive appraisal, which is the critical mechanism for resilience. However, the present study has several limitations and more research is necessary for these speculations to be conclusive.

## **Chapter 5**

### **Maternal and Child Reflective Functioning in Dyads in Good Versus Poor Diabetes Control: A Comparative Study.**

#### **Introduction**

The psychological dimension of T1D in childhood is a vital aspect in the course the illness takes. Across this thesis, we have understood the relationship between psychological aspects and T1D as bi-directional; on the one hand, T1D affects psychosocial functioning (e.g., by increasing vulnerability to mental health problems; Das-Munshi et al., 2007; Reynolds and Helgeson, 2011; Anderson et al., 2001) and on the other hand, the subject's psychosocial functioning affects the course of the illness. It does so directly, by affecting metabolic control (Guo et al., 2011; Helgeson et al., 2009) and, indirectly, through its influence on treatment adherence (Duke et al., 2008; Bearman and La Greca, 2002).

However, the mechanisms by which the psychological dimension and T1D are connected have scarcely been elucidated. In this respect, we have argued that a contemporary psychodynamic perspective rooted in an attachment-mentalizing approach might be particularly useful for understanding the phenomena and to inform both treatment and prevention for the diabetic population. This idea is supported by previous research in which this approach has been shown to be effective in the understanding of other chronic conditions (e.g., FSD; Luyten, Lemma, Van Houdenhove, Target and Fonagy, 2013). In our previous two studies, the relationship between attachment, mentalizing, stress and diabetes outcomes was analysed. The results of these previous studies suggested that RF has a particularly

important role in diabetes outcomes. Therefore, it seems important to investigate the relationship between RF and T1D in more detail.

However, one of the main limitations of Studies 1 and 2 was the use of self-report measures, which are known to have limitations. For example, one of the reasons the validity of self-report measures has been criticised is because they rely completely on introspective capacities (Sedikides and Strudes, 1995). The present study addressed this methodological limitation by using observer-rated measures of RF in both mothers and children.

Additionally, this study aimed to address two other limitations, which presented in our previous two studies: the lack of variability in diabetes outcomes measures and the presence of significant gender differences. With regard to the first limitation, we purposefully sampled two groups of children: those with good diabetic control (HbA1c levels below 7.7) and children with poor diabetic control (HbA1c levels above 7.7). In addition, we decided to only focus on boys in an attempt to further disentangle the role of RF and stress in children and mothers in relation to diabetes outcomes. As discussed in the previous chapters, dynamics in girls in relation to diabetes seem to be quite different and thus required a separate study, which is currently ongoing at the time of writing this PhD.

Therefore, the main purpose of the present study was to compare levels of RF in both mothers and male children with T1D between two groups: one in which the child currently presented good diabetes control and the other in which the child presented poor diabetes control. In addition, diabetes-specific quality of life and child's stress were measured using self-report measures.

Based on the literature reviewed in Chapters 1 and 2 and the findings of the first and second studies of this thesis, it was expected that:

- 1.) Mothers and children in the Good Diabetes Control Group (GDC) would present higher RF than mothers and children in the Poor Diabetes Control Group (PDC).
- 2.) Children in the PDC Group would present higher levels of stress than children in the GDC Group.
- 3.) Diabetes Specific Quality of Life would be higher in the GDC group and was expected to be positively correlated with RF in both mothers and children in both groups.

This is the first investigation, to our knowledge, to examine RF in mothers and children with Type 1 Diabetes based on observer rated measures.

The first section of this chapter will describe the methods and process of the research carried out. Following this, the results of the data analysis will be presented. Finally, a discussion of relevant findings will be formulated.

## **5.1 Methods**

### **5.1.1 Participants and Procedure**

Participants were 55 mother-child dyads, comprising 28 dyads in good diabetes control and 27 dyads in poor diabetes control.



Children were recruited from the Juvenile Diabetes Foundation of Chile (JDFC; see section 3.1.1). Parents registered in the foundation's database with children between 8 to 12-years-old with diabetes for more than 6 months, received an e-mail with an invitation letter containing the study details (see Appendix E). Those who showed interest in participating were contacted via e-mail or phone (as they preferred) to schedule the interview, and the consent form and information sheet were sent out to them. Following that, a visit to the JFDC office was scheduled for both mothers and children in order to complete the interviews. Mothers completed the Parent Development Interview (PDI) and children completed the Child Attachment Interview (CAI). Mothers also completed a survey on diabetes outcomes and the Pediatric Diabetes Specific Quality of Life questionnaire (PEDSQoL) and children completed the Stress in Children questionnaire (SiC). Just as in Studies 1 and 2, mothers were asked to report their child's previous three glycosylated haemoglobin exams (HbA1c) and the mean was used for analysis (See section 3.1.2 for details about the exam).

Participants were separated into two groups, which were formed on the basis of diabetes control level, HbA1c levels and PEDSQoL scores. The Good Diabetes Control Group (GDC) was formed of participants with a mean HbA1c level below 7.73. In contrast, participants with a mean HbA1c level above 7.73 were placed in the Poor Diabetes Control Group (PDC). As mentioned before, a common HbA1c target level is 6,5% or lower. HbA1c showed to be negatively correlated with PEDSQoL in the total sample, implying that higher HbA1c levels were associated with lower diabetes specific quality of life ( $r=-.39$   $p=.01$ ). In sum, the groups were formed based on a median split, together with a consideration of the general

standards of HbA1c, which generally considered HbA1c >7.5 as linked with poor control related problems (NICE, 2015; Diabetes UK, 2015; ADA, 2018).

. The present study was approved by the UCL Research Ethics Committee, Number 8899/002 (See Appendix F). Characteristics of each group are presented in Table 5.1 below:

**Table 5.1 Sample Characteristics**

	Mean (SD) or %	n		Mean (SD) or %	n
<b>Poor Diabetes Control Group: Mothers Information</b>			<b>Good Diabetes Control Group: Mothers Information</b>		
<b>Age (years)</b>	38.1 (6.0)	28	<b>Age (years)</b>	40 (7.8)	27
<b>Educational Level (%)</b>			<b>Educational Level (%)</b>		
Primary School	14.8	4	Primary School		
Secondary School	33.3	9	Secondary School	32.1	9
Technical Education	11.1	3	Technical Education	17.9	5
Bachelor Studies	37	10	Bachelor Studies	35.7	10
Postgraduate Studies	3.7	1	Postgraduate Studies	14.3	4
<b>Socioeconomic Status (%)</b>			<b>Socioeconomic Status (%)</b>		
Poverty	3.7	1	Poverty		
Low Middle	33.3	9	Low Middle	25	7
Middle	40.7	11	Middle	25	7
High Middle	7.4	2	High Middle	7.1	2
High	14.8	4	High	42.9	12
<b>Poor Diabetes Control Group: Children Information</b>			<b>Good Diabetes Control Group: Children Information</b>		
<b>Age (years)</b>	10.5 (2.1)	22	<b>Age (years)</b>	10.4 (1.8)	24
<b>Hba1c</b>	9.2 (1.4)	26	<b>Hba1c</b>	7.1 (0.5)	28
<b>Time Since Diabetes Onset (months)</b>	55 (33.8)	26	<b>Time Since Diabetes Onset (months)</b>	53.4 (28.5)	28

The mean age of mothers was 40 (SD=7.8) in the GDC and 38 (SD=6) in the PDC. Children were on average 10-years-old in both groups (SD=1.8 and SD=2.1, respectively). There were no significant differences in demographic features between GDC and PDC groups. The average time since T1D diagnosis was 54 months in the GDC group and 55 months in the PDC group. HbA1c levels were GDC group: M=7.1 (SD=0.5) and PDC group: M=9.2 (SD=1.4).

Both groups presented similar distributions regarding socioeconomic status and mother's educational level (see Table 5.1 for distributions). As mentioned in the introduction of this chapter, all the children in the sample were boys. Only one child did not complete the CAI.

### **5.1.2 Measures**

#### **Mother's Reflective Functioning**

**The Spanish version (Golano-Fornells, Perez-Testor and Salamero-Baro, 2018) of the Parental Development Interview (PDI) and Reflective Functioning Scale (RFS).** The Parent Development Interview (Aber, Slade, Berger, Bresgi, and Kaplan, 1985; Slade, Aber, Bresgi, Berger and Kaplan, 2004) is a 45-item interview aiming to examine parents' representations of their children, themselves as a parent, and their relationship with their children. Interviewees are asked to provide real-life examples of their child's behaviour, thoughts and feelings, which illustrate their

understanding of their own and their child's internal experience. For the present study, interviews were carried out by the first author (SC) and two other clinical psychologists. The first author was trained by Arietta Slade in June 2016. The author then trained two other psychologists to perform the interview. Maternal RF was measured using the PDI-Reflective Functioning Scale (PDI-RFS), a coding scale that was adapted from the RFS that was initially developed to be scored with the AAI. The RFS employs an 11-point scale using a manual that provides illustrations of different types and levels of RF responses, ranging from 1 (avoidance or active refusal to mentalize) to 9 (exceptionally rich, complete, and sophisticated understanding of mental states in interaction). An overall RF score was assigned following the guidelines in the manual. A complete description of the RFS coding system can be found in Table 5.2 below.

**Table 5.2. Examples of Different Levels of Parental Reflective Functioning\***

<b>RF Level</b>	
<b>-1 Negative RF</b>	Anti-reflective; bizarre; hostile; inappropriate "Why are you asking if I get angry? You're just trying to find bad things against me"
<b>0</b>	
<b>1 Absent RF</b>	Passively evasive; little or no hostility; disavowal explanations "I don't know. I really couldn't say"
<b>2</b>	
<b>3</b>	
<b>Questionable or low RF</b>	Uses mental state language but not reflectively; superficial; clichéd "She just wants this and wants that"
<b>4</b>	
<b>5 Definite or ordinary RF</b>	Uses non-clichéd mental state language reflectively "I think he felt sad and that's why he started clinging to me"
<b>6</b>	
<b>7 Marked RF</b>	Sophisticated RF on mental states more than once but not continually; complex; an interactive perspective "She was so happy and kept cuddling up and kissing me, and that made me happy"
<b>8</b>	
<b>9 Full or exceptional RF</b>	Full awareness of reflecting on mental states; sophisticated

*\*Taken from Fonagy, Target, Steele and Steele. (1998)*

Reliability estimates using the coding manual have been shown to be good, with internal consistency ranging from .78 to .95 (Slade, Grienberger, Bernbach, Levy, and Locker, 2005). Protocols were coded by two trained and accredited Spanish speaking coders; one being the author of this thesis, who was accredited as reliable by Arietta Slade in 2017. Coders were blind to which group each interview belonged. Moreover, the interviews carried out by the author were coded by the second coder in order to avoid bias, and vice versa.

Inter-rater reliability was calculated between the two independent coders based on 10 randomly selected interviews, using Intra-Class Coefficient (ICC) based on an absolute-agreement and 2-way mixed-effect model. ICC values were .83, CI

[.42, .96] for single measures and .91, CI [.66, .98] for average measures. These results indicate a good level of reliability (Portney and Watkins, 2000).

### **Child Reflective Functioning.**

**The Chilean version (Lecannelier, in press) of the Child Attachment Interview (CAI) and Child Reflective Functioning Scale (CRFS).** Child RF was measured using the Child Attachment Interview (CAI; Shmueli-Goetz, Target, Fonagy and Datta, 2008; Target, Fonagy, Shmueli-Goetz, Schneider and Datta, 2000) rated with the Child Reflective Functioning Scale (CRFS; Ensink, Target and Oandasan, 2013). The CAI is a semi-structured interview for 8 to 12-year-olds consisting of 13 questions. It was developed to assess children's attachment representations of their current relationships with primary caregivers. Children are asked to give adjectives to describe themselves and their attachment relationships, followed by requests for examples to illustrate why they used these adjectives. For example, children are asked the following questions: "Can you think of three words to describe your relationship with your mum?". For each word that the child gives, they are asked: "Can you give me an example that illustrates why you picked that word; of a time when your relationship was (e.g., loving)?" and: "Can you think of a time when your mum got angry with you? Tell me what happened." After each question children are asked about why they think the parents behaved in the way they did, how that made them feel and how they think their parents felt. The CAI was administered by the first author (SC) who was trained by Yael Shmueli Goetz in February 2017 (See

Appendix G). Another two clinical psychologists trained by SC also administered the interview.

The CRFS was developed to assess RF in middle childhood, rating the data gathered using the CAI based upon the Adult Reflective Functioning Manual developed by Fonagy, Target, Steele and Steele (1996), with modifications addressing developmental characteristics of children in an age range of 8 to 12-years-old. Children's responses are coded on an 11-point scale (ranging from -1 to 9) in terms of the child's ability to give an account of their capacity to make meaning of personal and interpersonal behaviours and interactions based on underlying mental states. The CRFS has shown high inter-rater reliability, with a median ICC of .93 (Ensink et al., 2013).

In the present study, child RF was rated by the thesis author and a child psychiatrist who was an accredited rater. Inter-rater reliability was calculated between both coders on 10 protocols. As for the PDI, for the codification of these interviews, raters were independent from the interviews codified, to avoid bias. ICC estimates and their 95% confident intervals were calculated using SPSS 24 based on an absolute-agreement and 2-way mixed-effects model. The obtained ICC value was .97, CI [.87, .99] for single measures and .98, CI [.93, .99] for average measures. ICC values indicate an excellent level of reliability (Portney and Watkins, 2000).

**Table 5.3. Examples of Different Levels of Child Reflective Functioning\***

Rating	Description
-1	Bizarre, disorganised response where mentalizing is actively avoided, or where there is an aggressive refusal to mentalize. Example: "When she gets cross? There is an angel dancing on her shoe."
0	Absence of mentalization. Example: "I don't know, it just is."
1	Descriptions in terms of physical or behavioral non-mental characteristics. Example: "She says*go to your room."
3	Unelaborated references to mental states when describing relationships. Example: "I like it, it is fun."
4	References to mental states, but with gaps that have to be filled in. Example: "When I feel sad, she like ... comforts me."
5	Clear description showing a solid mental state understanding, even if fairly simple. Example: "When she gets angry, she shouts, and I don't like it, but I know she does not really mean what she says and that I am alittle bit to blame."
7-9	Increasingly sophisticated mental state understanding, with 9 denoting exceptional and complete mental state understanding. Example: "When he gets angry, I also get angry at first, but then I feel guilty, because I know he helps me a lot, and when I forget my books at school it takes much longer, and he gets tired and has work to do too."

*\*Taken from Ensink, Bégin, Normandin and Fonagy (2016).*

## **Child's Stress**

**The Chilean version (Caqueo-Urizar, Urzúa and Osika, 2014) of the Stress in Children (SiC) (Osika et al., 2007).** The SiC is a 21-item questionnaire for school age children designed to assess perceived distress, levels of well-being and aspects of coping and social support. Participants are asked to rate how often they felt or thought a certain way during the last month, ranging from *never* to *very often* with higher scores meaning higher levels of stress. The SiC demonstrates high internal consistency with a Cronbach's alpha-coefficient of .79 for the complete test score and .79, .67 and .62 for the three subscales (lack of well-being (LWB), distress (D) and lack of social support (LSS), respectively). The SiC showed to be reliable in the Chilean population for the three subscales, (LWB, D and LSS) with a Cronbach's



alpha-coefficient of .80; .77 and .69 respectively (Caqueo-Úrizar et al., 2014). In this study, internal consistency for each scale showed to be good ( $\alpha=.75$ ;  $\alpha=.70$ ;  $\alpha=.70$ , respectively).

## **Diabetes Outcomes**

**The Chilean version (Varni, 2003) of the Paediatric Quality of Life Inventory Diabetes Module 3.2 Parent-Report (PEDSQoL 3.2 Diabetes Module; Varni et al., 1999).** This scale measures the child's parent-reported Diabetes-Specific Quality of Life. It assesses how well the illness has been integrated in the child's life and concerns several dimensions of diabetes care, which are reflected on the subscale. In this sense, the PEDSQoL can be considered an indicator of diabetes outcomes. It consists of 28 items divided into four subscales: (1) Diabetes Symptoms (11 items), (2) Treatment Adherence (11 items), (3) Diabetes Concerns (3 items; e.g., in the last month "It has been a problem for my child being worried about future diabetes complications" ), and (4) Diabetes Communication (3 items; e.g., in the last month "It has been a problem for my child to explain his illness to other people"). Responses are on a 5-point Likert scale (ranging from *never a problem* to *almost always a problem*) with higher scores meaning fewer problems (therefore, higher Diabetes Specific Quality of Life). Most scales in this measure exceeded the reliability standard of .70, with  $\alpha$ -coefficients for each subscale, as follows: Diabetes Symptoms (DS) .81; Treatment Barriers (TB) .68; Treatment Adherence (TA) .68; Worry (W) .81; Communication (C) .84. In the present study, the Cronbach's alpha on the PEDSQoL total score was  $\alpha=.80$ .

## **Demographic Information**

### **Socioeconomic Status Survey (Chilean National Institute of Statistics, 2011).**

The National Institute of Statistics of Chile's (INE) Socioeconomic Status Survey was used to measure socioeconomic status and education level. In this survey, participants are asked to select options from lists of goods, income and education levels; each option chosen by participants adds points to a total score which corresponds with one quintile within range from 0 to 1000. (High: from 823 to 1000; Middle: from 543 to 823; Middle low: from 341 to 543; Poverty: from 105 to 341; Extreme Poverty: from 0 to 105) (INE, 2011).

## **5.2 Data Analysis**

First, correlational analyses between study variables and demographics were performed in order to identify potential covariates. Second, a multivariate analysis of variance (MANOVA) was used to compare maternal and child RF and child stress between the GDC and the PDC groups, followed by univariate ANOVAs for each dependent variable. Third, correlation analyses were performed between the study variables for the whole sample and for each group separately.

## 5.3 Results

### 5.3.1 Correlations with Demographics

As seen in Table 5.4, correlations between the study variables and demographic characteristics were non-significant.

**Table 5.4. Pearson Correlations Between Study Variables and Demographics**

Features	CAI-RF	PDI-RF	HbA1c	PEDSQoL	SiC
<b>Educational Level</b>	.08	-.07	-.03	-.09	.01
<b>Mother's Age</b>	.05	-.03	.16	-.07	-.25
<b>Socioeconomic Status</b>	-.02	-.2	.01	.13	.09

Note: \*  $p < .05$ , \*\*  $p < .01$

### 5.3.2 Group Comparisons

MANOVA was used to determine significant differences in maternal RF and child RF between dyads in good diabetes control and dyads in poor diabetes control.

First, mothers in the GDC group scored higher on maternal RF than mothers in the PDC group ( $M = 5.3$ ,  $SD = 1.5$  and  $M = 4.4$ ,  $SD = 1.0$ , respectively) with a large effect size (Cohen's  $d = .70$ ). Similarly, children in the GDC group showed higher levels of RF than children in the PDC group ( $M = 5.0$ ,  $SD = 1.3$  and  $M = 4.0$ ,  $SD = 1.4$ , respectively), again with a large effect size (Cohen's  $d = .74$ ). Table 5.5 presents the differences between the groups in maternal and child RF.

Using Wilks' lambda, the differences between the two groups on the combined dependent variables was statistically significant ( $F(2, 52) = 4.00, p < .005$ ; Wilks'  $\Lambda = .866$ ; partial  $\eta^2 = .134$ ).

MANOVA results were followed up with univariate one-way ANOVA for each dependent variable, which revealed statistically significant differences in child RF between GDC and PDC groups and also in maternal RF between the groups ( $F(1, 53) = 7.762, p < .01$ ; partial  $\eta^2 = .128$  and  $F(1, 53) = 6.476, p < .05$ ; partial  $\eta^2 = .109$ , respectively).

In addition, univariate ANOVAs revealed a significant effect of child RF on diabetes outcomes ( $F(1,53)=7.76, p<.01$ ) and of maternal RF on diabetes outcomes ( $F(1,53)=6.47, p<.05$ ).

Finally, against expectations, the PDC group score on stress was not statistically different from the GDC group stress level ( $p=0.6$ )

**Table 5.5. Group Comparisons for Maternal and Child RF in 55 Mother-Child Dyads**

Variables	Groups	Mean	SD	F
Maternal RF	GDC	5.3	1.5	6,476*
	PDC	4.4	1.0	
Child RF	GDC	5.0	1.3	7,762**
	PDC	4.0	1.4	

*Note: RF, reflective functioning; \* $p < .05$ ; \*\* $p < .01$*

### 5.3.3 Correlations Between Study Variables

In the total sample, consistent with expectations, a negative correlation was found between HbA1c and both child and maternal RF ( $r = -.35$   $p < .001$ ;  $r = -.34$   $p < .001$ , respectively). Additionally, maternal RF was negatively correlated with stress (total) which was expected ( $r = -.30$   $p < .005$ )

*Diabetes symptoms* showed a positive correlation with child RF ( $r = .23$   $p < .005$ ) which was consistent with expectations. However, maternal RF was negatively correlated with *diabetes communication*, which was not expected ( $r = -.30$   $p < .005$ ). Further results in the total sample showed trends similar to the findings for each group separately and are presented below in Table 5.6.

**Table 5.6. Total Sample Matrix Correlation**

	<i>Diabetes QoL Dimensions</i>					<i>Child RF</i>	<i>Mother RF</i>	<i>Hba1c</i>
	<i>Communication</i>	<i>Symptoms</i>	<i>Concerns</i>	<i>Treatment</i>	<i>Total Score</i>			
<b><i>Stress Dimensions</i></b>								
<i>Lack of Social support</i>	-.04	-.25*	-.11	-.22	-.24*	-.01	-.16	.08
<i>Distress</i>	.08	-.36**	-.15	-.37**	-.34**	.04	-.23	.11
<i>Lack of Well-being</i>	.15	-.30*	-.26*	-.42**	-.34**	-.03	-.20	-.04
<i>Total</i>	.08	-.37**	-.21	-.41**	-.38**	-.00	-.24*	.09
<b><i>Child RF</i></b>	-.21	.23*	.21	.14	.16		.79**	-.35**
<b><i>Maternal RF</i></b>	-.30*	-.25	.21	.20	.19	.79**		-.34**

Note: \*  $p < .05$ , \*\*  $p < .01$ .

In the GDC group, as expected, stress showed to be negatively correlated with diabetes outcomes; all stress dimensions were significantly correlated with all the dimensions of diabetes-specific quality of life, except *communication* (see Table 5.6). Also HbA1c was, consistent with expectations, positively correlated with stress (total) in the GDC group ( $r = .37$   $p < .005$ ). Maternal RF was positively correlated with child RF ( $r = .84$   $p < .001$ ).

**Table 5.7. Groups Correlation Matrix**

Diabetes QoL Dimensions						Child RF	Maternal RF	Hba1c
Communication	Symptoms	Concerns	Treatment	Total Score				
Poor Diabetes Control Group								
Stress Dimensions								
Lack of Social support	-.07	-.09	.10	.10	.01	.07	.09	-.26
Distress	.15	-.44*	.07	-.37*	-.30	.09	-.20	-.16
Lack of Well- being	.19	-.21	-.11	-.30	-.21	-.05	-.29	-.17
Total	.12	-.31	.02	-.25	-.21	.04	-.18	-.24
Child RF	-.35**	.06	.18	-.15	-.09		.70**	-.04
Maternal RF	-.62**	-.01	.07	-.16	-.23	.70**		.02
Good Diabetes Control Group								
Stress Dimensions								
Lack of Social support	.07	-.35*	-.33*	-.53**	-.47**	-.02	-.29	.22
Distress	.00	-.36*	-.44*	-.45**	-.49**	.01	-.26	.42*
Lack of Well- being	.12	-.45**	.46**	-.70**	-.61**	.02	-.16	.29
Total	.08	-.47**	-.49**	-.68**	-.63**	.00	-.28	.37*
Child RF	-.32	.07	.14	.04	.02		.84**	-.25
Mother RF	-.30	.16	.25	.18	.15	.84**		-.22

Note: \*  $p < 0.05$ , \*\*  $p < 0.01$ .

The PDC Group presented a smaller number of significant correlations, as shown in Table 5.6. However, important results in the relationship between stress and diabetes were found. For example, *symptoms* was negatively correlated with *distress* ( $r = -.44$   $p < .005$ ), which was consistent with expectations. In this group, an unexpected finding emerged: diabetes *communication* was negatively correlated with both child and maternal RF ( $r = -.35$   $p < .001$ ;  $r = -.62$   $p < .001$ , respectively). Further results of the correlation analysis for the PDC group are presented in Table 5.7.

## 5.4 Discussion

This study aimed to investigate the relationships between child and maternal reflective functioning (RF), child's stress and child's diabetes outcomes, by comparing two groups clustered according to their achievement of diabetes control. It also intended to examine significant correlations between maternal and child RF, child's stress and child's diabetes outcomes.

The findings show that both maternal and child RF were higher in the good diabetes control group (GDC) than in the group with poor diabetes control (PDC). Similarly, both maternal and child RF were negatively correlated with HbA1c in the total sample. These results suggest that higher RF might be related with better diabetes outcomes. This interpretation is further supported by the finding that maternal and child RF were highly correlated in this sample in both groups. Still, it may also be that poor diabetes outcomes may negatively influence levels of RF in

both children and mothers, and the dyad may become trapped in a vicious cycle. Conversely, good diabetic control may foster mentalizing in both mothers and children. Further longitudinal research is needed in this regard.

Regarding stress, we unexpectedly found no differences between the PDC and GDC group. Yet, as expected, stress was negatively correlated with several dimensions of diabetes outcomes in both groups, implying that higher stress might be related to poorer diabetes outcomes. However, an unexpected result was that stress was not significantly correlated with RF. Another unexpected result was that in the PDC group, both maternal and child RF were negatively correlated with diabetes communication, implying that in this group, higher RF was related with poorer diabetes communication.

The finding that maternal and child RF are lower in the PDC group than in the GDC group, is in line with previous studies showing that higher levels of mentalizing are associated with resilience (Fonagy et al., 1994), which would foster positive health outcomes, while lower levels of mentalizing have been linked with stress-related health outcomes (Luyten and Fonagy, 2016). Specifically, it has been argued that mentalizing is an important mechanism involved in stress regulation (Luyten and Fonagy, 2016). In turn, stress has been linked with several health impairments, especially those associated with the HPA axis (McEwen, 2007; Gunnar et al., 2007), as has been discussed previously in this thesis (see Chapters 1 and 2).

The activation of stress would be partly linked with the experience of threat that the illness entails. In this respect, it has been argued that patients with chronic illnesses tend to relate to their illness as an internal object that modifies their affective



states (Schattner, Abu-Shakra and Shahar, 2008) and that this kind of relationship would imply a constant activation of arousal (Luyten and Fonagy, 2016).

We could consider that, in order to prevent the illness being experienced as a constant attack, the subject needs to integrate diabetes as part of his/her internal psychological world, instead of relating to diabetes as a threatening object. We think that this process is supported by mentalizing the illness, i.e., by understanding how the experience of diabetes is linked with mental states. For example, by being able to understand how the patient thinks or perceives diabetes to be affecting their subjectivity in terms as broad as individual identity, and as narrow as everyday anxieties connected with its management. At the same time, by the patient being able to identify and understand how his/her own emotions can affect diabetic control (directly, by affecting BG levels through endocrinological mechanisms and, indirectly, through the effect that emotions can have upon behaviours required for proper management). We think that this connection between diabetes aspect and mental aspect (i.e., mentalizing diabetes) is crucial for the achievement of good diabetes control, and the results of the present study support this idea.

Moreover, in childhood, the understanding of minds develops within attachment relationships (Stern, 1985; Allen, 2013, Fonagy et al., 2002) and, similarly, diabetes treatment is also performed in coordination with caregivers. The process mentioned above would, therefore, include not only the child's mentalizing but also the mother's mentalizing. It has been shown that the understanding of minds occurs from the outside-in (Gergely & Unoka, 2008). That is to say, the social context in which the child develops widely influences the way in which they conceive what minds are.

For this reason, in the present thesis we have argued that, in order to understand the reflective process by which the child integrates diabetes in his/her internal psychological world, the inclusion of the caregiver's ability to understand his/her own mind as well as his/her child's mind, is crucial. The results presented here give further confirmation to this idea, through the finding that a mother's RF is highly associated with her child's diabetes outcomes.

However, the identification of specific mechanisms by which mentalizing and diabetes outcomes are connected remain to be discovered. We have advocated stress as a plausible candidate in this respect, but the results of the present study only partially support this hypothesis; although the PDC group presented higher levels of stress than the GDC group, these differences were not statistically significant. Moreover, stress was not shown to be significantly correlated with RF, which was unexpected. Nevertheless, there is compelling evidence linking mentalizing with the regulation of stress (Fonagy and Luyten, 2009; Luyten et al., 2012) and evidence linking stress with poor diabetes outcomes (Johnson, 1980; Fisher et al., 1982; Surwitt and Schneider, 1993; Lloyd et al., 1999; Konen et al., 1993; Wiesli et al., 2005). Similarly, in this study, higher stress levels were linked with poorer diabetes outcomes.

Therefore, it is plausible to think that in the present study, the absence of an association between stress and RF can be explained by other factors. One explanation might reside in the self-reporting nature of the measure we used for stress, which relies on the individual's perception and acknowledgment of his/her levels of stress. It is known that stress is a highly complex construct (Cicchetti and Walker, 2001; Gunnar and Quevedo, 2007, McEwen, 2007) with multiple levels of

response, such as behavioural, genetic and physiological (Nolte, Guiney, Fonagy, Mayes and Luyten, 2011). It is therefore highly likely that some dimensions of the stress response occur outside the subject's awareness.

Moreover, the act of reporting stress would also be influenced by individual differences in several aspects, such as personality. For example, an experimental study (Silva, Vivanco-Carlevari, Martinez, Salazar, Barrientos and Krause, 2017) found that subjects classified as introjective, presented the highest cortisol levels in the sample but reported the lowest levels of perceived stress, while subjects in the anaclitic group presented the opposite pattern of response. The findings by Silva et al. (2017) reflect important individual differences in the reporting of stress, which can be related to either the awareness of the experience of stress or to report tendencies. However, the specific nature of the differences in stress reporting needs further research in order to be elucidated.

In this thesis, we have claimed for both biological and psychosocial mechanisms by which stress affects diabetes. However, it is possible that the measure used in this study captures only some dimensions of stress. If this is the case, one would expect that biological measures of stress (for example, saliva cortisol samples) would be able to assess stress levels more accurately, giving an account of the dimensions of the stress response that might be connected with the process of mentalizing.

In any case, our measure of stress did show important relationships with diabetes outcomes. This is an important finding supporting the consideration that stress could imply poor diabetes outcomes and/or that poor diabetes outcomes could lead to stress. This is in line with the idea widely discussed in this thesis regarding

the effect of stress on metabolic control *directly*, and on treatment adherence *indirectly*. We should also add here a further direction in the relationship between stress and diabetes outcomes: it could also be the case that being in poor control may lead to distress because of the numerous adversities involved in a dysregulated diabetes. For example, the pressure put on the patient by health providers when HbA1c levels are high, the threat of future complications, phantasies related to death, and the specific symptoms of higher/lower than expected BG levels. It is important, therefore, to highlight that stress can be both cause and consequence of poor diabetes control.

Another important finding of this study is that maternal RF and child RF were highly positively correlated with each other in both groups. This result is consistent with studies in younger children showing that individual differences in children's understanding of mental states would be explained by maternal reflective functioning (Meins et al., 2001; Ruffman, Slade and Crowe, 2002; Slade et al., 2005; Sharp and Fonagy, 2008). Considering the above, it is plausible to think that the intergenerational transmission of mentalizing could be impaired in dyads challenged by T1D. The onset of a life-threatening illness in a child is an undoubtedly stressful experience for a caregiver (Whittemore et al., 2012; Moreira et al., 2013; Kovacs et al., 1997). Therefore, it would not be surprising to find interference in the transmission of mentalizing process within the caregiver-child dyad due to increased parental stress. It has been proposed that the caregiver's ability to regulate their own stress level has a crucial effect on the child's strategies for stress regulation (Nolte, Guiney, Fonagy, Mayes and Luyten, 2011). However, it is known that even efficient strategies for the regulation of stress can fail in the face of a chronic activation of

stress (Luyten et al, 2012), such as may be aroused in a parent faced with their child's chronic illness.

Therefore, considering the role of parental stress, the present results may implicate the development of interventions aiming to foster the proper regulation of stress in parents of newly diagnosed children. Specifically, interventions designed to prevent impairments in mentalizing and, in this way, to prevent consequent mental and general health difficulties.

Finally, an unexpected result found with the PDC group, was that mother and child RF were negatively correlated with diabetes communication. The PEDSQL scale of diabetes communication is concerned with the extent to which the child is able to explain his/her illness to other people and to exchange diabetes-related information with health-providers. This unforeseen finding may be explained by considering that the child's capacity to communicate regarding diabetes might be linked with their own ability to mentalize the negative affects triggered by a difficult issue. Thus, in some individuals the ability to express diabetes-related issues might be linked with the specific capacity to mentalize diabetes, separate from the general capacity to reflect. This would be in line with what was discussed in Chapter 4 regarding the role of a symptom-specific RF, which has been seen to work independently from general RF in a number of psychological disorders (Rudden, Milrod, Target, Ackerman and Graf, 2006; Kullgard, Persson, Moller, Falkenstrom and Holmquist, 2013; Ensink, Berthelot, Bernazzani, Normandin and Fonagy, 2014). The latter, supports our idea that diabetes-specific reflective functioning is an important area requiring elucidation through future research.

Our results provide relevant evidence for the role of both child and caregiver RF in the course of T1D, supporting our claim that an attachment-mentalizing approach may be an important framework for understanding the psychological dimension of T1D in children. These findings could be applied to the development of psychological interventions for children with Type 1 diabetes and their caregivers, specifically those that focus on their reflective functioning and its role in the incorporation of diabetes into their internal psychological world.

However, our study had several limitations that will be discussed below.

### **Limitations**

The exclusion of girls from the sample is an obvious limitation of the study in that, despite having the clear advantage of increasing homogeneity, it restricts extrapolation of results to a broader population and therefore the generalizability of the findings as a whole.

It should be noted, however, that there are important gender differences (in both diabetes and mentalizing) that make boys with T1D a population needing special attention. Specifically, young males with T1D show worse treatment adherence (Naar-King et al 2006), worse metabolic control (Grey, Lipman, Cameron, and Thurber, 1997) and lower frequency of blood glucose testing (Bearman and La Greca 2002).

Moreover, the prevalence of T1D has been found to be higher (by a factor of up to two) among males in certain countries (e.g. Sweden, in the 15-39 age group - Wandell and Carlsson, 2013). Similarly, Gale and Gillespie (2001) found an approximate 3:2 male-to-female ratio of T1D sufferers in a population of European origin, aged 15-40.

Regarding processes linked to mentalizing, girls have been found to be more likely than boys to seek out other people (social support) as a strategy for emotion regulation (Brenner and Salovey, 1997). Similarly, mother/daughter dyads have been shown to spend more time talking to each other (Tannen, 2006), and to make greater use of emotional language in their narratives than mother/son or father/daughter dyads (Fivush, Brotman, Buckner and Goodman, 2000). They have also been shown to have closer and warmer relationships than mother/son dyads (Shanahan, McHale, Crouter, & Osgood, 2007; Tucker, McHale, & Crouter, 2003). Importantly, one study showed that, in boys but not girls, emotion regulation deficits were correlated with decreased metabolic control (Graziano et al., 2011). In terms of psychosocial deficits, this is important evidence of the need to study the specific requirements of boys with T1D. Indeed, studies of gender disparities in psychopathologies like antisocial behaviour (Ehrensaft, 2005), eating disorders (Ambwani, Slane, Thomas, Hopwood & Grilo, 2014) and depression (Nolen-Hoeksema, 1987) have claimed that such differences must be acknowledged if we are to identify and understand the diverse treatment needs of these populations. The above findings confirm the advantage of our sample being male-only.

However, our sample had other limitations, such as its relatively small size and its lack of sociodemographic variability (in that most mothers were relatively highly educated).

Another important limitation of the study, as mentioned earlier, was that the role of stress remains to be determined.

Future studies should include more accurate measures of stress. It would be particularly beneficial to study the role of stress and RF in the diabetic population

from an experimental or quasi-experimental approach with both biological measures of stress and repeated measures. Moreover, the present study should be replicated in a female population and research on a sample reflecting a broader spectrum of society might prove useful. Considering that the present study was performed within a specific cultural context, cross-cultural studies could also be fruitful.

In conclusion, the results of the present study give substantial support to the model presented in this thesis. Overall, our third study was able to demonstrate that both maternal and child RF may have a substantial role in diabetes outcomes. However, the mechanisms require further elucidation.

In the next chapter, the issues outlined here will be revisited from a broader perspective in which the findings of all three studies will be considered.



## **Chapter 6**

### **General Discussion**

The present thesis aimed to develop a contemporary psychodynamic approach for diabetes and to validate some of the key features of this approach in order to inform treatment and prevention. Overall, our findings provide substantial support for the theoretical model that guided this thesis. Yet, we also obtained some unexpected findings, which require a revision of the theoretical model outlined in Chapter 2.

In this chapter, we will first revisit the main findings of our three studies. Next, we discuss the limitations of our work and the possible direction future research might take. Finally, we present the implications for both clinical practice and policy making.

#### **6.1 Main Findings**

The main findings of this thesis can be summarized as follows: (a) counterintuitive findings concerning diabetes control; (b) gender differences; (c) complex dyadic interactions, and, (d) expected findings. A discussion of the main findings follows.

## **Never Judge a Book by its Cover: Counterintuitive Findings Concerning Diabetes Control**

To a significant degree, the findings across the three studies that were unexpected, shed valuable light on relevant issues for clinical practice. Essentially, these findings can be summarized with the following statement: *good diabetes control is not always synonymous with good general health.*

Our results suggest that good diabetes control can imply negative mental health outcomes and future general health complications. Specifically, within the group of girls, maternal attachment avoidance was linked with good diabetes control (HbA1c), with one possible explanation being that, good control might be part of a coping strategy characterized by compulsive self-reliance (see Chapter 3). The strategy used by these girls is one commonly found in avoidant-attached individuals, implying decreased social contact and avoidance of expressing negative emotions (Manassis, 2001). This would carry high psychosocial and metabolic costs due to a tendency towards isolation (Mikulincer and Shaver, 2007) and a suppression of distress, which has been linked to both an increase in allostatic load (McEwen, 2007) and consequent impairments related to the HPA axis (Miller et al., 2007). The latter may lead to problems in diabetes outcomes, if we consider the harmful role of stress in its course (Marcovecchio and Chiarelli, 2012; Johnson, 1980; Fischer et al., 1982).

Indeed, this is in accordance with general psychoanalytic principles, namely, that behaviour may have a defensive function. Thus, behaviours that seem adaptive in the short-term, might result in maladaptive outcomes in the longer term. It is important to note that the strategy discussed here is also of a dyadic nature: girls adapt to the avoidant strategies of their mothers.

Another finding in line with the above, is that high bodily awareness in girls was the only dimension of mentalizing associated with good diabetes-specific quality of life. As discussed in Chapter 3, bodily awareness can be associated with anxiety (Fonagy et al., 1987). Although it may be useful for accurately recognizing BG levels, leading to good metabolic control, when linked to high anxiety, it may also lead to further diabetes complications because anxiety has been observed to directly affect metabolic control (Grabill et al., 2010).

This finding seems extremely relevant if we consider that good diabetes control is generally interpreted as a sign of general positive health outcomes. Although there is some awareness regarding the risk of mental health problems among the diabetic population, these are generally thought to be associated only with poor diabetes control. For example, the NICE guideline (2015) for children with Type 1 diabetes indicates that children and young people with HbA1c levels above 8.5% should be referred for a psychological intervention in order to improve their blood glucose control. Similarly, guidelines for medical practice usually include warnings about the signals of anxiety, and they advise that people with T1D are at a higher risk of developing eating disorders. However, these guidelines fail to mention the possibility that good diabetes control (HbA1c in optimal levels) may also be a potential sign of problems if it is observed alongside a particular psychosocial context (for example, the child being more in charge of their diabetes than their caregivers).

In considering our results, it is possible that a group of patients achieves good diabetes control at the expense, in the short-term, of their psychosocial integrity, and with a high risk of failure regarding their physical health in the long-term.

However, in this respect, the design of our study only allows us to speculate. Longitudinal studies would be valuable concerning this issue, in order to test the long-term costs of the compulsive self-reliance strategy found in girls with T1D. Also, a consideration of the potential moderating role played by the father or a second caregiver, siblings and peers would add fruitful information in this area.

### **Gender or Sex Differences?**

Differences in boys and girls presented an important trend across Studies 1 and 2. The most important differences were found in regard to the role of attachment and stress in diabetes.

First, secure attachment was related to better diabetes outcomes in boys, but not in girls. Second, maternal avoidance had an opposite effect on boys versus girls. While boys with avoidant mothers presented poor diabetes control, girls presented good diabetes control. And third, the effect of stress (and particularly mother's stress) among boys was the opposite of the effect among girls. While boys presented poor diabetes outcomes when maternal stress was high, girls presented good diabetes outcomes in that same situation.

There are at least two complementary interpretations of these findings. First, a sociocultural perspective (i.e., the image of females as maternal and a symbol of 'care' in the Latin American culture) might help to explain these gender differences. However, if we consider that gender differences are a highly complex issue, as well as a sensitive topic, this idea needs to be treated more comprehensively, especially considering the potential social implications of this type of discussion. When studying such phenomena, we believe that it is necessary to consider the different dimensions

involved, which are neither purely cultural nor purely biological. For this reason, an in-depth investigation of gender differences in attachment, mentalizing, stress and diabetes is a task that goes beyond the aims of this thesis, but that remains an essential issue to be addressed in the near future.

Second, beyond the cultural dimension, gender or sex differences in the response to stress may also play an important role. In this respect, a recent study showed that stress affects males differently than females, especially in regard to bodily systems regulated by gonadal hormones (Bangasser, Eck and Ordones-Sanchez, 2018). For example, in females, ovarian hormones promoted resilience to some stress responses. Similarly, it has also been argued that the prevalence of psychiatric disorders presents very differently among males than among females (Seedat, Scott and Angermeyer, 2009). However, gender differences have scarcely been considered in health research. Indeed, only fairly recently, the National Institute of Health in the United States has taken action to encourage researchers to consider sex as a biological variable in animal studies (Clayton and Collins, 2014).

However, these interpretations are largely hypothetical and our results do not offer an in-depth account of how these significant gender differences operate. More research in this area is needed.

Accordingly, we suggest three different study designs that might be useful to investigate this issue further.

First, a study within a **prospective birth cohort research programme**, to which one would add measures of attachment and stress in children and caregivers from the early years and in different periods. It is likely that a proportion of the sample would present with diabetes at some point. This sub-sample would be asked to

provide information on their diabetes outcomes (i.e., treatment adherence, metabolic control). Additionally, access to family background, genetic and biological information would provide further covariates for data analysis, which would look for relationships between attachment, stress and T1D outcomes in boys and girls separately. A comparative study of caregivers and children with T1D versus those without T1D would then be performed to test differences in stress levels and patterns of attachment between the two groups. In this way, it would be possible to test whether the T1D group presents with higher levels of stress than healthy peers, and if distributions of attachment categories are different across the two samples.

Within the T1D sample, changes in attachment after diabetes onset would also be explored, and the efficiency of strategies to deal with T1D followed across time to determine how effective they are in the short and long terms in promoting both physical and mental health, and how they relate to attachment patterns and differences between males and females.

A second proposed study, to disentangle the gender differences in attachment stress and T1D in caregiver-child dyads, would be a **transcultural study**. We have argued that cultural aspects play a role in how well boys and girls take care of their bodies. These differences can be seen in at least two cultural situations: the transmission of self-care within the mother-child dyad, which is influenced by the representation of women as innate caregivers (Montecino, 1993), and the importance of body control in western cultures, which is a social imperative directed more at females than males (Vertinsky, 1998).

In order to disentangle this cultural phenomenon, it would be interesting to explore differences in the transmission of self-care within caregiving relationships

across different cultures. Also, a comparison between dyads with T1D and those without T1D (across cultures) would be interesting, in order to assess the role of diabetes in relation to this self-care configuration.

A third investigation would be a **qualitative study**, with a between-groups design, aiming to compare the experiences of being the primary caregiver of a male child with T1D versus a female child with T1D. In this study, measures of attachment (for both caregivers and children) would be used to explore the association between aspects of the caregiver-child relationship and attachment categories. In this way, we could test in-depth our controversial results about gender differences in the influence of avoidant attachment on the self-care strategies developed by children.

These suggested lines of research would be useful in understanding gender differences more comprehensively and systematically.

However, it should be noted that gender difference emerges from a highly complex interaction of cultural, socio-historical and biological factors. Thus, research on its specific causes would require knowledge of the nature of these mechanisms (e.g., biological, social) in order to test them directly. Although the studies suggested here are more likely to identify patterns than to attribute specific causes, they could be instrumental in determining which of these factors should be examined further.

In sum, there is enough evidence to suggest that gender differences constitute a highly relevant issue for consideration in mental health research. Accordingly, our results support this idea. We found that gender differences showed a particularly relevant role regarding the effect of maternal issues. This complex and rather unresolved topic of the impact of caregivers on their children and of children on their caregivers also arose in our findings, as we discuss below.

## **The Complexities of Dyadic Interactions: Who Influences Who?**

Even though the cross-sectional nature of our study does not allow us to draw strong conclusions with regard to interactional processes, our findings suggest that such interactional processes may be key to an understanding of the course of diabetes in children. First, mother and child RF were highly positively correlated. Second, mother RF was related to diabetes outcomes in boys. Both these findings suggest that studies observing the course of diabetes in children should routinely include a focus on caregivers. Classical psychoanalytic notions of the importance of considering the child and his/her caregiver as a 'whole' can be found in the work of several authors. These include, Winnicott, and his memorable statement, "there is no such thing as a baby" (1952); Bowlby, most specifically the studies he made with Robertson and Rosenbluth (1952), in which they made a claim for not separating hospitalized children from their caregivers; and Anna Freud, who went even further in her conception of this vital cycle, claiming that, where health is concerned, the mother-child unity is key, "through all the phases of childhood into adolescence" (Freud, 1952, p.79).

Similarly, our results suggest that, if the psychological aspects of the caregiver are so closely linked to the psychological and illness-related issues of the child, when working on the psychological dimension of T1D with children, the active participation of the caregiver in the process needs to be considered, including observing the psychological aspects of both, separately and in interaction.

Results from the mediation analyses, in particular, point to the importance of interactional processes. We found that child mentalizing is related to diabetes



outcomes through its influence on the mother's stress. This result suggests that mother's stress affects the child's diabetes outcomes, but also that this effect is triggered by the child's own capacity or inability to mentalize. In Chapter 3, we proposed the possibility that the mother's perception of their child as relatively autonomous in understanding their own mind, may provide them with a sense of relief, which would explain the effect of a child's issue upon a mother's issue. It is important to note, that the results mentioned above were only found in boys, giving further support to the idea of caregiver-child influences being bi-directional. Indeed, as we have seen, in girls, attachment avoidance features (which may be transmitted from caregiver to child) appear to set in motion a coping strategy characterized by the denial of distress.

Studies which claim the environment as an overwhelming influence usually fall into blaming caregivers unnecessarily and neglect the role of factors such as temperament (Rothbart and Ahadi, 1994). At the other extreme, controversial studies that claim parents have no influence on their children (for example, Plomin et al., 1997; Pinker, 2002) may be harmful in naturalizing and justifying preventable early adversities (i.e., maltreatment) that are actually well-documented vulnerability factors (Lyons-Ruth, 2003).

Conversely, our results suggest a role for both parties – observing influences from the child to the parent and from the parent to the child; possibly with a non-linear causality that is highly interweaved, thus it is difficult to identify where each effect starts. Moreover, it is important to mention that the caregiver-child dyad is also part of a broader context in which transgenerational influences, epigenetics and socio-historical factors, to name but a few, also play an essential role.

## **A Smooth Encounter with Theory: Expected Findings**

Overall, results from our three studies suggest the important role of mentalizing in diabetes outcomes. A key finding in this respect is that both mother and child RF were significantly higher in the Good Diabetes Control (GDC) group than in the Poor Diabetes Control (PDC) group in Study 3. Although the specific mechanisms of this association needs to be further elucidated, previous findings on the role of mentalizing in other chronic illnesses (Luyten and Fonagy, 2016; Luyten et al., 2013) may be informative here.

It can be argued that high RF fosters good diabetes outcomes through direct and indirect mechanisms linked to stress regulation. High RF in both children and their caregiver may constitute the basis of an integration of diabetes within the child's internal psychological world, which would prevent the experience of the illness as being a constant attack from within. We have argued that the stress response aroused by diabetes may be related to an experience of the illness as something separate from the subject, i.e., as an internal object with the power of changing affective states outside the individual's control (Schattner et al., 2008).

It is possible that a proper integration of the illness within the child's internal psychological world would prevent the chronic activation of stress that this experience of the illness arouses. In childhood, this process of integration would occur within the caregiver-child dyad and involve the capacity of both members to reflect and link diabetes aspects with mental aspects.

Figure 6.1 illustrates how this process would occur within the mother-child dyad in a simplified form. As can be seen in the illustration, both mother and child

would be confronted with a threatening issue that triggers stress-related mental states. In this context, we argue that dyads with high RF would be able to approach the threat positively; RF may encourage the process of integrating the illness into the child's subjectivity, by allowing a connection to be made between child's aspects and diabetes aspects.

In order to integrate the illness as part of his/herself, the child needs a caregiver who is able to mentalize i.e., to reflect upon both his/her own internal mental experiences and those of the child (Ensink and Mayes, 2010; Slade, 2005). At the same time, the caregiver would need to mentalize his/her own mental states regarding his/her child's illness (for example, guilt or fear) in order to be able to mentalize their child's mental states, as aroused by the illness. Additionally, this process would foster the child's own capacity to mentalize him/herself (Fonagy, Gergely and Target, 2007), which in our study is reflected in the fact that mother and child RF were highly positively correlated.

This process allows both members of the dyad to regulate stress, fostering good health outcomes through a process of resilience (Fonagy et al., 1994). Additionally, dyads with high RF are more likely to be involved in interpersonal situations that are beneficial for good diabetes outcomes, probably because they have higher epistemic trust, which is the capacity to perceive others as a reliable source of knowledge (Gergely, Egyed and Kiraly, 2007; Fonagy and Allison, 2014; Fonagy, Luyten and Allison, 2015). For example, they are more prone to trust in the health provider and the medical treatment. They may also be more likely to be involved in diabetes-related community activities and thus more open to diabetes-education, which is crucial for diabetes treatment (Ellis et al., 2004).

Moreover, high RF is related to interest in exploring the internal world and the capacity to recognize emotions (Fonagy et al., 2002). This may also promote good diabetes outcomes by supporting the proper identification of emotions related to fluctuating BG levels and acting accordingly to prevent episodes of hyper or hypoglycaemia.

In contrast, in the case of poor diabetes outcomes and low RF, the opposite process can be seen to be active. As has been observed in patients with FSD (Luyten et al. 2013, Luyten and Fonagy 2016), poor diabetes outcomes and the associated symptomatology (e.g., abnormal BG levels) and complications, can trigger a stress response. In turn, stress impairs mentalizing, producing interpersonal problems (including problems with health-providers) which can lead to further stress. This stress affects diabetes outcomes (directly and indirectly), and thus a vicious cycle is activated.

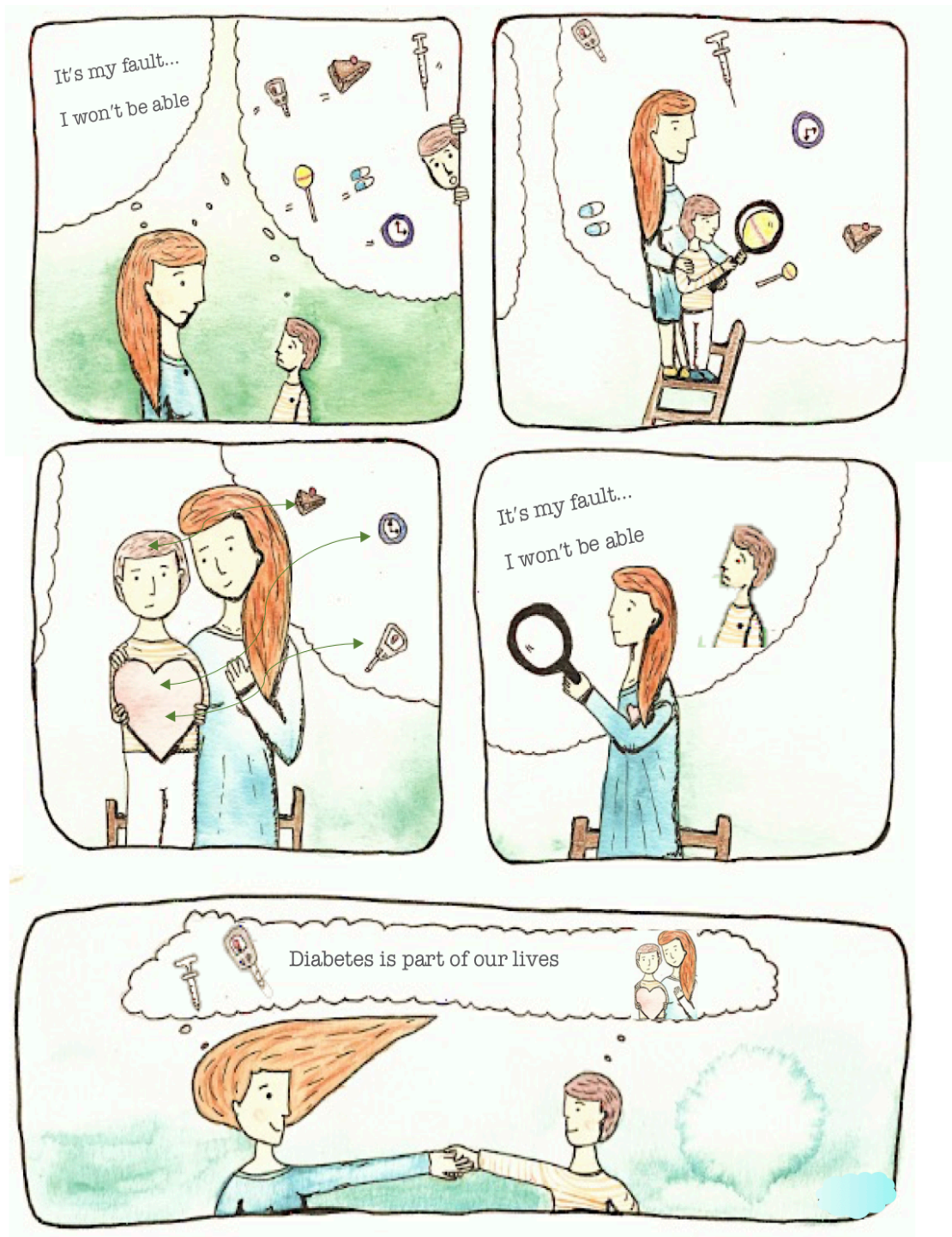
In this respect, findings from our preliminary and largely explorative study on the role of diabetes-specific RF on both diabetes outcomes and mental health provides further evidence for these assumptions.

Although the study was not able to thoroughly demonstrate the measure's reliability, its preliminary validation results provide valuable insight regarding the effect that over-mentalizing diabetes can have on resilience, through an excessive focus on the illness and the consequent inability to disengage. As discussed in Chapter 4, the main mechanism of resilience postulated by the PASTOR theory (Kalisch et al., 2015) is the presence of a positive re-appraisal style, which implies the capacity to re-assess a given threat in a way that attenuates the stress response associated with it. In the process of changing the value conferred to the stimuli, the

subject will need to be able to inhibit the negative appraisal, in a process called “interference inhibition”. We think that patients with T1D who present an over-focus on the illness, have an impaired capacity to inhibit the interference from the constant re-traumatizing trigger, that their mental representation of the illness implies. Taking Kalisch et al.’s (2015) theory into account, we think that this tendency will, in turn, impair the process of resilience, leaving the patient vulnerable to psychopathology. The latter would be reflected in our results, in which D-RF positively correlated with psychopathology and stress.

However, because the design of our study does not allow us to interpret causality, the above considerations remain a speculation. Further research with a more complex design will be required to elucidate these processes further. This and the other limitations of our studies will now be discussed.

**Figure 6.1 Mother and Child Linking Diabetes with Internal Psychological States.**



*Costa-Cordella, S and Barrera, P. (2018)- Pancreas Mother Illustration*

## 6.2 Limitations and Directions for Future Research

We have outlined several limitations in the studies reported in this thesis. Here, we summarize some of the main issues, and their implications for future research.

First, the cross-sectional observational design prevents us from drawing conclusions regarding causality and the specific influences between mother and child. Future research should consider the use of longitudinal data in order to clarify the role that the strategies used by patients may have over time. Additionally, longitudinal data would allow for a closer examination of the complex linkages between mother-child interactions, with the possibility of using an actor-partner interdependence model. Further, the use of experimental design would be fruitful, especially to clarify the role of stress; ideally using biological measures of stress such as cortisol levels.

Secondly, our sample presented little variability in several areas, which could have affected the results. Mothers were generally highly educated which may have an influence on the higher levels of RF presented. Indeed, in our third study the mean RF was 4.8 in mothers and 4.5 in children in the total sample, which is higher than in other studies (for example, in the study of Ensink et al. 2016 the mean RF was 3.7 in mothers and 2.8 in children).

Another demographic factor that could have had an influence was maternal age. Previous studies have shown that RF increased with maternal age (Luyten et al., 2017). The mean age of mothers was 39 in the three studies, which is higher

than the mean age of mothers with 8 to 12-year-old children in Chile which is 32 (INE, 2017).

An important limitation regarding our sample is that it was composed of people who attend the Juvenile Diabetes Foundation of Chile (JDF), which is an institution that supports people with T1D, particularly in providing children and caregivers with diabetes education through workshops and group activities. It is very likely that people involved in this type of activity represent a small proportion of the diabetic population that has a higher level of RF, especially considering our earlier speculation regarding epistemic trust. In this sense, our sample also reflected a generally healthy group of people, with relatively well-controlled diabetes (as reflected in the average HbA1c levels of 8.4, 8.5 and 8.1, respectively) and lower levels of psychopathology. For example, people in our sample differ from the patients analyzed in the studies by Fonagy and colleagues (1989-1994; see Chapter 2) in which children were referred to psychotherapy precisely because of their highly dysregulated diabetes and evident psychosocial problems. Thus, it might be that the group of diabetic patients who are more vulnerable to the type of problems linked to mentalizing do not have enough representation in our sample.

Thirdly, we did not fully address the problem of gender differences. Future studies should consider this, perhaps supported by the use of an experimental design in order to disentangle the self-reliant strategy observed in girls within the present sample.

Finally, our measure for diabetes-specific RF would have benefited from further development. Future research should consider a broader pool of items and include the careful conduction of a validation study. This is highly important in order



to be able to measure the impact of future interventions based on mentalizing. It is very likely that such interventions will enhance a specific dimension of RF connected with diabetes which general measures of RF are not able to capture.

### **6.3 Implications**

Probably the most important implication of our findings is that both mentalizing and the inclusion of caregivers in clinical work should be taken into account when working with the psychological dimension of T1D.

Taken together, our findings support the necessity and feasibility of developing mentalization-based interventions for diabetic children and their caregivers. Such interventions would aim to foster mentalizing in parents and children in order to promote the proper regulation of stress and, in this way, prevent both the consequent mental and general physical health impairments, which are a known risk for this population.

A second broad recommendation that emerges from our findings concerns health practitioners working with children with T1D. A consideration of the child's and caregiver's capacity to reflect upon the illness may be crucial in understanding other aspects of their diabetes coping strategy, and in this respect, finding the proper balance will be central. For example, health practitioners that identify an absence of a proper understanding of the psychological dimension of the illness, in either child or caregiver, may refer them for psychosocial interventions that will help them to consider the implications on both their mental health and diabetes control. In contrast, a patient who is excessively focused on their diabetes may be showing

signs of psychosocial difficulties connected with hyper-mentalizing and the incapacity to disengage from stressful issues.

Finally, our results may inform policymakers in ways that will promote a better status of health for the diabetic population. Our results show that fostering mentalizing abilities in children with Type 1 diabetes and their caregivers may be an effective strategy for prevention by promoting a positive incorporation and consequent control of the illness. In turn, better-controlled diabetes would result in less short and long-term complications and thus an important reduction of costs for the public health system.

**APPENDIX A**  
**INVITATION LETTER, INFORMATION SHEETS AND CONSENT FORMS**  
**STUDIES 1 AND 2**



**An invitation to take part in a study:**

**Attachment and Mentalization in the Diabetic Mother-Child Dyad**

We hope this e-mail finds you and your family well.

We would like to invite you and your child to take part in a research study that aim to understand better the relationship between mothers and children with diabetes in order to provide them with more efficient treatments.

Your participation would consist in answer several questionnaires about your experience of the relationship with your child and how are you feeling in general. This should take around 40-50 minutes of your time.

In addition, we will ask your child to complete three short questionnaires about their experience having diabetes and about how they feel in their main relationships. This should take around 20-30 minutes of your child's time.

We are interested in finding out how the different styles of relationship between mothers and their diabetic children could be related with how they deal with the tasks that diabetes implies and with the level of control of the illness that they achieve. We are interested in explore the subjective experience of the mothers (that is, how they feel, what they think, what it is happening in their minds) regarding her child's diabetes as well as the subjective experience of the child regarding his/her own diabetes

We think that could be helpful to understand these things better in order to develop interventions that consider both mother 's and child's perspectives in order to help them deal with diabetes in a better way.

If you agree to take part and your child and you agree to him/her to take part, you only need to write an e-mail to the Juvenile Diabetes Foundation (Miss Francisca Mena) who already sent you this invitation, indicating that you are interested in participate.

After that, she will send you an e-mail with two websites links: the first one will contain the questionnaires to be answered by you, and the second one will contain the questionnaires to be answered by your child.

Before the questionnaires are displayed, an information sheet with all the information related to this study will be shown and we will ask you to read this information very carefully.

The questionnaires will be displayed on your screen only if the participant (you and your child) after reading this information, accept to participate.

Once your participation is completed, you will see an electronic £5 voucher as a thank you for your time and effort.

Your participation will be anonymous. We will not have access to your personal details and we will be able to contact you only through the Juvenile Diabetes Foundation, without knowing your name or contact details.

.If you want to contact the researchers of this study directly, you can write an e-mail to: [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk)

If you decide now or at a later date that you do not wish to participate in this research you are free to withdraw at any time without giving a reason.

**Thank you for taking the time to read this invitation! We hope to hear back more from you.**

*(this document was showed in Spanish)*



## INFORMATION SHEET FOR CHILDREN

### **Attachment and Mentalization in the Diabetic Mother-Child Dyad**



A group of psychologists are doing a research study and would like to ask for your help. Research means finding out more about something. It is a way we try to find out the answer to questions.

#### **Why is this project being done?**

Some children with diabetes have problems to control their diabetes in the way that doctors ask them to do.

Sometimes, the way in which children take care of their diabetes depends on how they feel and how the things are going at school or at home. We would like you to help us find out more about this.

#### **Why have I been chosen to take part?**

We ask the Juvenile Diabetes Foundation to invite all the children between 8 and 12 years old and their mothers to take part of this study. This is because we would like to know more about how the children with diabetes of your age feel and think, so then we would be able to help children of your age to feel better.

#### **What do I have to do to take part?**

If you agree to take part in our project, you will have to answer some short questions with multiple choice options. This will not be a test like in school, there are no correct or wrong answers. You can answer what you want and you can skip the questions that you feel that you do not want to answer.

You are free to stop participating at any time without explaining why, and with no penalty.

### **Will joining in help me?**

We cannot promise the study will help you but what we discover might help other children with diabetes to live better.



### **Do I have to take part?**

You do not have to take part. You can say no and no one will be cross or upset. If you say yes, but later change your mind then that's ok as well. Just tell your parents that you do not want to still answering the questionnaires.

### **Will anyone find out if I am on this study or what I answered?**

Your name and the answer that you give will be kept a secret- only the people who are doing the research will be able to see your answers, but without knowing that those answers are yours.

### **Did anyone else check the study is OK to do?**

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research is conducted by a team from a university called University College London, in UK, and it has been approved by the group of people that check the researches.

### **What do I do now?**

Take time to decide whether or not you want to take part, and please ask us or your parents if there is anything that you do not understand. If you have questions, you can e-mail us on: [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk).

**Thank you very much for your help!!!**



*(this document was showed in Spanish)*



## **INFORMATION SHEET- MOTHERS**

### **Attachment and Mentalization in the Diabetic Mother-Child Dyad**

We would like to invite you to take part in a research study that aim to understand better the relationship between mothers and children with diabetes in order to provide them with more efficient treatments.

Before you decide whether you would like to take part, it is important for you to know why the research is being done and what it will involve. Please take time to read this information sheet carefully and discuss it with others if you wish. If there is anything that is not clear, or if you would like to receive more information, please do not hesitate to contact Stefanella Costa Cordella on [REDACTED] or at stefanella.cordella.15@ucl.ac.uk.

#### **The aim of the study**

We are interested in finding out how the different styles of relationship between mothers and their diabetic children could be related with how they deal with the tasks that diabetes implies and with the level of control of the illness that they achieve. We are interested in explore the subjective experience of the mothers (that is, how they feel, what they think, what it is happening in their minds) regarding her child's diabetes as well as the subjective experience of the child regarding his/her own diabetes.

#### **Why is the study being done?**

We know from previous studies that the way in which people with chronic illness deal with them, is related with how the main relationships that they have are set, because the way in which people deal with relationships is similar to the way in which they face many aspects of illnesses.

We also know from previous studies that caregivers of diabetic children are exposed to be affected in their well-being and quality of life because of the burden of taking care of a child with a chronic illness.

Another thing that we have seen in previous studies, is that children with diabetes are more likely to be affected psychologically by the illness and its implications.



Taking this information together, we think that could be helpful to understand these things better in order to develop interventions that consider both mother 's and child's perspectives in order to help them deal with diabetes in a better way.

### **Why have we been asked to take part?**

We are contacting you because you are a member of the Juvenile Diabetes Foundation of Chile and your child is of the age that we consider significant to be studied. Because your child is 8 to 12 years old, he or she is living a stage in which the responsibilities for the care of the illness continue to be largely of the parents, but at the same time, the necessity to give them some autonomy regarding their treatment is emerging more and more everyday. After this period, your child will be an adolescent, and because we know that for both psychological and endocrine reasons this stage could be complicated, we consider relevant paying attention to the phase that precede it, in order to develop ways to prevent some of the difficulties that arise in adolescence.

### **What will happen if we take part?**

If you agree to take part, we would ask you to complete 6 questionnaires about your experience of the relationship with your child and how are you feeling in general. The questionnaires will be displayed on your screen only if you, after reading this information, accept to participate. This should take around 40-50 minutes of your time.

If some items are difficult for you or you simply do not want to answer them, please feel free to skip them, **you do not have to answer any question that you do not want to.**

If either now or during the process of answering the questionnaires you want to stop participating, please consider that **you can decide to not participate at any time without any penalty.**

If you decide to answer the questionnaires, and you and your child decide that she or he will answer the child's questionnaires, following the completion of this process a £5 voucher will be displayed on the screen as a thank you for your time and effort. You can print it and take it to the Juvenile Diabetes Foundation where you will be able to redeem your voucher in the counter at the entrance of the foundation's building.

### **Am I going to receive the results of the study?**

At the end of the project, after analysing all the information gathered from all participants, we will send you, through the foundation, a newsletter summarizing the findings of the study. No individuals will ever be mentioned in these newsletters – we will just summarize what we found overall.

**What will happen with the results of this study?**

Our intention is to use this information to develop a theory that serves as the base to the development of new psychological treatments as well as information useful for different health providers to improve the way the treatments are addressed. We aim to publish a paper with some of the analysis that would arise from the information collected in this study in an academic journal. As mentioned above, no individuals will ever be mentioned in this paper.

**Is there any risk of discomfort?**

We hope that you find the questionnaires interesting and useful, and do not envisage that the things we will ask you will cause significant discomfort. However, some questions can make you think in personal experiences that sometimes can be difficult to deal with and/or that you consider too intimate. Please remember that you do not have to answer any questions that you do not want to. Also, if you want to talk to a qualified person about any of the things raised in this questionnaires we will be happy to help with that. You can write to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk) if you have any question or if you want us to contact you with qualified professionals. In addition, we assure you that this information will be treated in the strictest confidence and anonymity. The researchers of this study will not have access to any of your personal information (not even your name).

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8899/001

**Do I have to take part in this study?**

It is up to you whether or not you take part in this study. If you do decide to take part, you will be asked to sign a consent form (will be displayed on your screen after you read this information sheet). If you decide now or at a later date that you do not wish to participate in this research you are free to withdraw at any time without giving a reason.

**Will the information about my child or about me be available to anyone?**

All information collected from you during the course of this research will be kept strictly confidential and anonymous.

**Who will have access to the research records?**

Only members of our research team will be able to look at the information we collect. The record of your answers will be identified by a number. Only the psychologist of the Juvenile Diabetes Foundation (Miss Francisca Mena) will have access to a worksheet in which your participant number will be linked to your e-mail address. The research team of this study will not have access to that

worksheet. In the case that we need to contact you for a potential follow-up study, we will give to Miss Francisca Mena your participant number and she will send you our information.

### **How to contact the researchers?**

If you would like to know more about this research you can contact Stefanella Costa Cordella on [REDACTED]. If you prefer email, you can contact us on: [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk)

If you have any concerns about this or if you wish to make a complaint about the conduct of the study you can contact the Principal Researcher using the details below for further advice and information:

Dr. Patrick Luyten  
Director of PhD in Psychoanalytic Studies  
Research Department of Clinical, Educational and Health Psychology  
University College London  
1-19 Torrington Place.  
London WC1E 7HB  
[p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk)

If you have any doubt or concern about your rights as a participant in this research you can contact the Medical Doctor Counsellor of the Juvenile Diabetes Foundation using the details below:

Dr. Franco Giraudo  
Fundación Diabetes Juvenil  
Lota 2344, Providencia.  
Santiago de Chile  
0223673900  
[fgiraudo@diabeteschile.cl](mailto:fgiraudo@diabeteschile.cl)

**Thank you for taking the time to read this information sheet!**

*(this document was showed in Spanish)*

**INFORMATION SHEET- PARENT/GUARDIAN****Attachment and Mentalization in the Diabetic Mother-Child Dyad**

We would like to invite your child to take part in a research study that aim to understand better the relationship between mothers and children with diabetes in order to provide them with more efficient treatments.

Before you decide whether you would like to take part, it is important for you to know why the research is being done and what it will involve. Please take time to read this information sheet carefully and discuss it with others if you wish. If there is anything that is not clear, or if you would like to receive more information, please do not hesitate to contact Stefanella Costa Cordella on [REDACTED] or at stefanella.cordella.15@ucl.ac.uk.

**The aim of the study**

We are interested in finding out how the different styles of relationship between mothers and their diabetic children could be related with how they deal with the tasks that diabetes implies and with the level of control of the illness that they achieve. We are interested in explore the subjective experience of the mothers (that is, how they feel, what they think, what it is happening in their minds) regarding her child's diabetes as well as the subjective experience of the child regarding his/her own diabetes.

**Why is the study being done?**

We know from previous studies that the way in which people with chronic illness deal with them, is related with how the main relationships that they have are set, because the way in which people deal with relationships is similar to the way in which they face many aspects of illnesses.

We also know from previous studies that caregivers of diabetic children are exposed to be affected in their well-being and quality of life because of the burden of taking care of a child with a chronic illness.

Another thing that we have seen in previous studies, is that children with diabetes are more likely to be affected psychologically by the illness and its implications. Taking this information together, we think that could be helpful to understand these things better in order to develop interventions that consider both mother 's and child's perspectives in order to help them deal with diabetes in a better way.

### **Why have we been asked to take part?**

We are contacting you because you are a member of the Juvenile Diabetes Foundation of Chile and your child is of the age that we consider significant to be studied. Because your child is 8 to 12 years old, he or she is living a stage in which the responsibilities for the care of the illness continue to be largely of the parents, but at the same time, the necessity to give them some autonomy regarding their treatment is emerging more and more everyday. After this period, your child will be an adolescent, and because we know that for both psychological and endocrine reasons this stage could be complicated, we consider relevant paying attention to the phase that precede it, in order to develop ways to prevent some of the difficulties that arise in adolescence.

### **What will happen if we take part?**

If you agree that your child takes part, we would ask your child to complete 4 questionnaires about his/her experience of the relationship with his/her mother, with his/her diabetes, and how is he/she feeling in general. The questionnaires will be displayed on the screen only if you, after reading this information, accept to participate, and only if your child accept the information written for him/her that will be displayed after your agreement.

This should take around 20-30 minutes of your child's time.

If some items are difficult for your child or he/she simply do not want to answer them, he/she is free to skip them, **your child does not have to answer any question that he/she does not want to.**

If either now or during the process of answering the questionnaires your child wants to stop participating, please consider that **your child can decide to not participate at any time without any penalty.**

If you and your child decide that he/she will answer the questionnaires, and the mother of the child has answered or will answer the mother's questionnaires, following the completion of this process a £5 voucher will be displayed on the screen as a thank you for your time and effort. You can print it and take it to the Juvenile Diabetes Foundation where you will be able to redeem your voucher in the counter at the entrance of the foundation's building.

### **Am I going to receive the results of the study?**

At the end of the project, after analysing all the information gathered from all participants, we will send you, through the foundation, a newsletter summarizing the findings of the study. No individuals will ever be mentioned in these newsletters – we will just summarize what we found overall.

### **What will happen with the results of this study?**

Our intention is to use this information to develop a theory that serves as the base to the development of new psychological treatments as well as information useful for different health providers to improve the way the treatments are addressed. We aim to publish a paper with some of the analysis that would arise from the information collected in this study in an academic journal. As mentioned above, no individuals will ever be mentioned in this paper.

### **Is there any risk of discomfort?**

We hope that your child finds the questionnaires interesting and useful, and do not envisage that the things we will ask your child will cause discomfort. However, some questions can make your child think in personal experiences that sometimes can be difficult to deal with.

Please remember that your child does not have to answer any questions that he/she does not want to. Also, if you want to talk to a qualified person about any of the things raised in this questionnaire we will be happy to help with that. You can write to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk) if you have any question or if you want us to contact you with qualified professionals in the area where you live.

In addition, we assure you that this information will be treated in the strictest confidence and anonymity. The researchers of this study will not have access to any of your personal information (not even your names).

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8899/001

### **Does my child have to take part in this study?**

It is up to you and your child whether or not he/she takes part in this study. If you do agree that your child takes part, you will be asked to sign a consent form (that will be displayed on your screen after you read this information sheet). After that, an information sheet written in an age-appropriate way will be displayed for your child to read it and to agree with, in order to display the questionnaires for your child. If you or your child decide now or at a later date that you do not wish to participate in this research you are free to withdraw at any time without giving a reason.

### **Will the information about my child or about me be available to anyone?**

All information collected from you during the course of this research will be kept strictly confidential and anonymous.

### **Who will have access to the research records?**

Only members of our research team will be able to look at the information we collect. The record of your answers will be identified by a number. Only the

psychologist of the Juvenile Diabetes Foundation (Miss Francisca Mena) will have access to a worksheet in which your participant number will be linked to your e-mail address. The research team of this study will not have access to that worksheet. In the case that we need to contact you for a potential follow-up study, we will give to Miss Francisca Mena your participant number and she will send you our information.

### **How to contact the researchers?**

If you would like to know more about this research you can contact Stefanella Costa Cordella on [REDACTED]. If you prefer email, you can contact us on: [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk)

If you have any concerns about this or if you wish to make a complaint about the conduct of the study you can contact the Principal Researcher using the details below for further advice and information:

Dr. Patrick Luyten  
Director of PhD in Psychoanalytic Studies  
Research Department of Clinical, Educational and Health Psychology  
University College London  
1-19 Torrington Place.  
London WC1E 7HB  
[p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk)

If you have any doubt or concern about your rights as a participant in this research you can contact the Medical Doctor Counsellor of the Juvenile Diabetes Foundation using the details below:

Dr. Franco Giraudo  
Fundación Diabetes Juvenil  
Lota 2344, Providencia.  
Santiago de Chile  
[REDACTED]  
[fgiraudo@diabeteschile.cl](mailto:fgiraudo@diabeteschile.cl)

**Thank you for taking the time to read this information sheet!**

*(this document was showed in Spanish)*



## Attachment and Mentalization in the Diabetic Mother-Child Dyad

### Consent form for children:

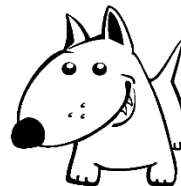
Thank you very much for your help!!!

Now that you read the previous information, we would like to ask you some short questions just to be sure that you understood what is your participation about. If you need to ask something to the people that are doing this research, you can either contact us by clicking the option "Contact us" in the right side of this web site or by writing an e-mail to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk). If you are agree with the sentences below, please tick the boxes on their side. We will send automatically a copy of this page to your mother's email, so you can have it.

### **If yes, please tick the following:**

- ☐ I have read the Information Sheet and understand what the study is about.
- ☐ I have had the opportunity to ask any questions I wish to ask.
- ☐ I understand that my name and my answers will be kept a secret and only the people who are doing the research will see my answer but without knowing that are mine.
- ☐ I understand that I am free to stop taking part in this study at any time without any problem.
- ☐ I understand that I do not have to take part in this study if I do not want to.
- ☐ I have the names and telephone numbers of the people of the research in case I want to ask them something
- ☐ I agree that the research project named above has been explained to me and I agree to take part in this study.

Thank you very much for your help!!!



*(this document was showed in Spanish)*





## **Attachment and Mentalization in the Diabetic Mother-Child Dyad**

### **Consent form:**

Thank you very much for your interest in taking part in this research.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You can either contact us by clicking the option "Contact us" in the right side of this web site or by writing an e-mail to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk). After your agreement, you will be sent a copy of this Consent Form to your e-mail automatically. Keep and refer to at any time.

Please remember to read the Information Sheet before agree with this form. Again, if you have any questions arising from the Information Sheet, please do not hesitate to contact us for more information before you decide whether to take part.

### **If yes, please tick the following:**

- ☐ I have read the Information Sheet and understand what the study involves.
- ☐ I have had the opportunity to ask any questions I wish to ask.
- ☐ I understand that the research team will not have access to my personal information and that my answers will be kept anonymous.
- ☐ I understand that I am free to withdraw from the study at any time without giving a reason.
- ☐ I understand that I do not have to take part in this study
- ☐ I give consent to be contacted by the research team, through the Juvenile Diabetes Foundation, in the future for further research studies (this is optional).
- ☐ I have the names and telephone numbers of the research team in case I have any queries in the future
- ☐ I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

*(this document was showed in Spanish)*



## **Attachment and Mentalization in the Diabetic Mother-Child Dyad**

### **Consent form for Parent/Guardian:**

Thank you very much for your interest in taking part in this research.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You can either contact us by clicking the option "Contact us" in the right side of this web site or by writing an e-mail to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk). After your agreement, you will be sent a copy of this Consent Form to your e-mail automatically. Keep and refer to at any time.

Please remember to read the Information Sheet before agree with this form. Again, if you have any questions arising from the Information Sheet, please do not hesitate to contact us for more information before you decide whether to take part.

### **If yes, please tick the following:**

- ☐ I have read the Information Sheet and understand what the study involves.
- ☐ I have had the opportunity to ask any questions I wish to ask.
- ☐ I understand that the research team will not have access to my child's personal information and that my child's answers will be kept anonymous.
- ☐ I understand that my child is free to withdraw from the study at any time without giving a reason.
- ☐ I understand that my child does not have to take part in this study
- ☐ I give consent to be contacted by the research team, through the Juvenile Diabetes Foundation, in the future for further research studies (this is optional).
- ☐ I have the names and telephone numbers of the research team in case I have any queries in the future
- ☐ I agree that the research project named above has been explained to me to my satisfaction and I agree that my child takes part in this study.

*(this document was showed in Spanish)*

**APPENDIX B**  
**NOTIFICATION OF ETHICAL APPROVAL STUDIES 1 AND 2**

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**UCL RESEARCH ETHICS COMMITTEE  
ACADEMIC SERVICES**



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6<sup>th</sup> July 2016

Dr Patrick Luyten  
Division of Psychology and Language Sciences  
UCL

Dear Dr Luyten

**Notification of Ethical Approval**

**Re: Ethics Application 8899/001: Attachment and mentalization in children with diabetes and their mothers**

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until 6<sup>th</sup> July 2017.

Approval is subject to the following conditions.

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.
3. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely

**Professor John Foreman**  
**Chair of the UCL Research Ethics Committee**

Cc: Stefanelle Cordella, Applicant

Academic Services, 1-19 Torrington Place (9<sup>th</sup> Floor),  
University College London  
Tel:   
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

## **APPENDIX C**

### **STUDY 1 DEMOGRAPHICS**

### **CORRELATIONS MATRIX**

	All				Girls				Boys			
	Mother's age <sup>1</sup>	Socioeconomic level <sup>2</sup>	Educational level <sup>2</sup>	Child's age <sup>1</sup>	Mother's age <sup>1</sup>	Socioeconomic level <sup>2</sup>	Educational level <sup>2</sup>	Child's age <sup>1</sup>	Mother's age <sup>1</sup>	Socioeconomic level <sup>2</sup>	Educational level <sup>2</sup>	Child's age <sup>1</sup>
<b>ECR Dimensions</b>												
Avoidance	-.010	.092	-.194	.016	-.172	.060	-.192	-.063	.114	.126	-.189	.043
Anxiety	-.072	-.030	.011	-.052	-.320	-.021	-.088	-.100	.128	-.084	.052	-.088
<b>Total Score Security Scale</b>	.073	-.078	.052	-.117	.160	.073	.060	-.024	.045	-.202	.057	-.135
<b>PRFQ Dimensions</b>												
Pre-Mentalizing Modes	-.150	.078	-.065	-.099	-.317	.167	.059	-.276	.053	.018	-.203	.143
Certainty about Mental States	.104	-.043	-.113	-.072	-.095	-.127	-.219	-.055	.261	.035	-.060	-.174
Interest and Curiosity in Mental States	.105	.289*	-.165	-.305**	-.116	.387*	-.107	-.361*	.288	.181	-.221	-.311*
<b>Dimensions EAQ</b>												
Differentiation of emotions	.080	-.089	.140	-.090	.065	-.012	.137	-.080	.105	-.143	.120	-.078
Verbal sharing of emotions	.025	.129	-.020	-.013	-.103	-.009	.146	.183	.170	.265	-.096	-.109
Not hiding emotions	-.134	.219	-.128	-.213	-.262	.365*	-.013	-.173	.024	.129	-.232	-.184
Bodily awareness	.141	-.336**	.154	.061	.045	-.444*	.068	.134	.209	-.255	.205	.033
Attending to other people's emotions	-.019	.072	.058	.399**	.111	.039	.029	.478**	-.133	.089	.084	.334*
Analyses of own emotions	-.027	.148	-.055	-.194	-.048	.357*	-.104	-.357*	.010	-.070	.022	-.011
<b>Total</b>	.031	.013	.068	-.021	-.064	.036	.148	.040	.136	-.023	.045	.001

\* $p < .05$ ; \*\* $p < .01$

**APPENDIX D**

**D-RF QUESTIONNAIRE**

### D-RFQ

Below you will find 10 sentences about how you may think and feel about diabetes. Please read each sentence and tick the box you think describes best how you think and feel.

#### An example

For example, if you read a sentence that says:

“I love to play basketball”

and you really do not like basketball, you can tick box number 1, because you do not feel that this sentence is similar to what you think.

5	4	3	2	1
Very Much	Somewhat	Neutral	Not Much	Not at All
Like Me	Like Me		Like Me	Like Me
				X

Another example, if you read a sentence that says:

“I like to play with my brother all the time”

and you do like to play with him but sometimes you prefer to play with other people, you can tick the box number 4.

5	4	3	2	1
Very Much	Somewhat	Neutral	Not Much	Not at All
Like Me	Like Me		Like Me	Like Me
	X			

1. Since I have had diabetes, I have felt emotions that I have never felt before.

5	4	3	2	1
Very Much	Somewhat	Neutral	Not Much	Not at All
Like Me	Like Me		Like Me	Like Me

2. My glucose levels depend only on what I eat and how much exercise I do.

5	4	3	2	1
Very Much	Somewhat	Neutral	Not Much	Not at All
Like Me	Like Me		Like Me	Like Me

3. I don't know what other people think about my diabetes

5	4	3	2	1
Very Much	Somewhat	Neutral	Not Much	Not at All
Like Me	Like Me		Like Me	Like Me



4. I think that it is normal to sometimes feel angry about having diabetes

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

5. Sometimes I imagine what it will be like living with diabetes when I get older

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

6. I know exactly what other people think about me because I have diabetes

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

7. Sometimes I feel sad or angry because I have diabetes and I just want to stop taking care of it.

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

8. Since I have had diabetes, the relationship with my mother has changed.

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

9. It is very difficult for me to talk about my diabetes with friends that don't have diabetes

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

10. When I feel sad, nervous, anger or excited, I think that these emotions may influence my glucose levels.

5	4	3	2	1
Very Much Like Me	Somewhat Like Me	Neutral	Not Much Like Me	Not at All Like Me

*(this questionnaire was showed in Spanish)*

## **APPENDIX E**

### **INVITATION LETTER, INFORMATION SHEETS AND CONSENT FORMS**

#### **STUDY 3**

## **Diabetes and the mother-child relationship**

We hope this e-mail finds you and your family well.

We would like to invite you and your child to take part in a follow-up study of our research that aims to understand better the relationship between mothers and children with diabetes in order to provide them with more effective treatments.

Your participation would consist of an interview of around 60 minutes. We will ask you some questions about your relationship with your child and your general experience of being a parent.

In addition, we will ask your child to participate in a shorter interview about his/her relationship with you and his/her feelings about diabetes. This should last around 45-60 minutes.

Both interviews will be videotaped for analysis purposes and will be deleted after one year. Only the researcher will have access to this information, which will be stored securely on a private, password-protected PC.

We are interested in finding out how different styles of relationship between mothers and children influence how well they cope with the task of managing diabetes and the level of control they achieve over the illness. We are also interested in exploring the personal experience of mothers (that is, how they feel, what they think, what is happening in their minds) regarding their child's diabetes, as well as the experience of the child regarding his/her illness

We think this could be helpful in developing clinical services that consider both the mother's and child's perspectives in order to help them deal with diabetes in a better way.

If you are willing to take part – and you and your child agree that he/she will also participate –, you need only reply to this e-mail confirming this.

We will then send you another e-mail with an information sheet telling you more about this study. We would encourage you to read this very carefully. After that, we will send you some possible dates for you to book an appointment at the Juvenile Diabetes Foundation, where the interview will take.

We will give you a paper-based copy of the information sheet on the day of the interview.

If you decide now or at any later date that you do not wish to participate in this research you are free to withdraw immediately, without giving us a reason.

**Thank you for taking the time to read this invitation! We hope to hear back from you.**



*(This document was sent to participants in Spanish)*

## **INFORMATION SHEET FOR CHILDREN**



### **Diabetes and the mother-child relationship**

A group of psychologists are doing a research study and would like to ask for your help. Research means finding out more about something. It is a way we try to find out answers to questions.

#### **Why is this project being done?**

Some children with diabetes have problems controlling their diabetes in the way that doctors ask them to do.

Sometimes, the way in which children take care of their diabetes depends on how they feel and how things are going at school or at home. We would like you to help us find out more about this.

#### **Why have I been chosen to take part?**

Some time ago we asked the Juvenile Diabetes Foundation to invite all the children between 8 and 12 years old and their mothers to take part in our study. You and your mum participated by answering a survey. Now we want to know a little bit more about how the children with diabetes of your age feel and think, so we can try to help them feel better.

#### **What do I have to do to take part?**

If you agree to take part in our project, we will meet with you and ask you some questions. This interview will be videotaped so we can check the answers that you gave. Only the interviewer will have access to this video and after watching it she will delete it.

Please remember that there are no right or wrong answers to our questions. You can answer in any way you want. You can also tell the interviewer that you do not want to

answer a question if that is the case.

Also, you are free to stop the interview at any time, without explaining why. We will understand and will not ask you any more questions.

**Will joining in help me?**

We cannot promise the study will help you but what we discover might help other children with diabetes to live a better life.

**Do I have to take part?**

You do not have to take part. You can say no and no one will be cross or upset. If you say yes, but later change your mind then that's ok as well. Just tell the interviewer that you do not want to keep answering the questions and everything is going to be fine.

**Will anyone find out if I am on this study or what I answered?**

Your name and the video will be a secret - only the person who is doing the interview will be able to see the video because it will be encrypted with a secret password.

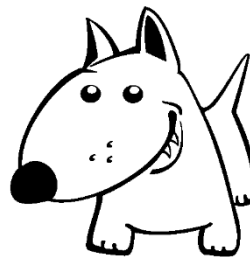
**Did anyone else check the study is OK to do?**

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research is conducted by a team from a university called University College London in the UK, and it has been approved by their Research Ethics Committee.

**What do I do now?**

Take time to decide whether or not you want to take part, and please ask us or your parents if there is anything that you do not understand. If you have questions, you can ask the interviewer before the interview starts, and also afterwards by writing an e-mail to: [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk).

**Thank you very much for your help!!!**



*(this document was showed in Spanish)*

**Participant Information Sheet For Mothers**

UCL Research Ethics Committee Approval ID Number: 8899/002

**Mentalizing Diabetes in the Mother-Child Dyad**

Division of Psychology and Language Sciences, University College London.  
Researcher: Stefanella Costa Cordella ([stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk))  
Principal Researcher: Patrick Luyten ([p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk))

We would like to invite you to take part in a research study that aims to understand better the relationship between mothers and children with diabetes in order to provide them with more effective treatments.

Before deciding if you would like to take part, it is important for you to know why the research is being carried out and what it will involve. Please take time to read this information sheet carefully and discuss it with others if you wish. If anything is unclear, or if you would like more information, do not hesitate to contact the researcher on +56998889682 or at [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk).

**The aim of the study**

We want to find out how the relationship between mothers and children affects the way they cope with the task of managing diabetes and the level of control they achieve over the illness. We also want to explore the personal experience of mothers (that is, how they feel, what they think, what it is happening in their minds) regarding their child's diabetes, as well as the experience of the child regarding his/her own diabetes.

**Why is the study being done?**

We know from previous studies that the way in which people deal with chronic illness is linked with how they relate to other people. In key respects, managing relationships is just like dealing with aspects of illness.

We also know from previous studies that the wellbeing and quality of life of caregivers of diabetic children can be affected by the burden of taking care of a child with a chronic illness.

Another thing that we have seen in previous studies is that children with diabetes are more likely to be affected psychologically by the illness and its implications. Taking this together, we think it would be helpful to understand these things better in order to develop interventions that consider both the mother and child's perspectives to help them deal with diabetes in a better way.

### **Why have we been asked to take part?**

We are contacting you because you took part in a survey during the first part of our research and expressed an interest in being contacted for a follow-up study. We are now interested in exploring the psychological aspects of looking after children with type 1 diabetes in more depth through a one-to-one interview.

### **Do I have to take part in this study?**

It is entirely up to you to decide whether or not to take part. If, after reading this information sheet, you choose to take part you will be contacted again and asked to sign a consent form. You can withdraw from the study at any time without giving a reason. If this happens you can decide what will happen to the data you have provided up to that point.

### **What will happen if we take part?**

If you agree to take part, we will ask you some questions, in person, about your experience of the relationship with your child. This is a standard interview that has been used in several studies around the world.

If certain questions are difficult to answer, or you simply do not want to answer them, please tell the researcher and she will move on. **You do not have to answer any question that you do not want to.**

If at any moment you want to stop participating, **you can do so without having to explain why.**

If you decide to take part in the interview, following the completion of this process £15 will give it to you as a thank you for your time and effort.

The whole process should take 40-50 minutes of your time.

### **Will the interview be recorded and how will the recording be used?**

This interview will be videotaped for analysis purposes. The videotape will be safely stored on an encrypted hard disk, with the password known only by the researcher. The recording will be transcribed and only the members of the research team will have access to this text. You will be identified in the text only by

an ID number - your name will not appear in any record. The videotape will be deleted after analysis (one year after the interview takes place).

### **What are the possible disadvantages and risks of taking part?**

We hope that you find the interview interesting and useful, and do not envisage that the things we will ask you will cause significant discomfort. However, some questions might make you think about personal experiences that are difficult to deal with and/or that you consider too intimate. Please remember that you do not have to answer any questions that you do not want to. Also, if you want to talk to a qualified person about any of the issues raised in the interview we will be happy to help with that. You can write to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk) if you have any questions or if you want us to put you in touch with qualified professionals.

### **What are the possible benefits of taking part?**

We will use the information you provide to develop a theory of how new psychological treatments for children with type1 diabetes and their caregivers can be designed, and to help health providers improve the support they currently provide.

### **What if something goes wrong?**

We hope that your participation in this research will be a positive experience. However, if you need to complain about any aspect of your participation, you can contact the Principal Researcher of this study (details provided below). If you are not happy with the response, you can write to the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

### **Will my taking part in this project be kept confidential\*?**

All information we collect about you during the course of the research will be kept strictly confidential. Your interview will be saved with an ID number, so your name will not appear in any of our records. The video and transcript of your interview – and all resulting analysis – will be stored on an encrypted hard disk, with the password known only to the researcher. You will not be identifiable in any ensuing reports or publications.

#### **\*Limits to confidentiality**

- Confidentiality will be maintained as far as is possible. However, the researcher has a duty to report to relevant authorities information received which suggests possible harm/danger to the participant or others.



- Please note that absolute confidentiality cannot be guaranteed due to the limited size of the participant group.
- Confidentiality will be respected subject to legal constraints and professional guidelines.
- Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. We would inform you of any circumstances that might limit your confidentiality.

## **Data Protection Privacy Notice**

### **Notice:**

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). UCL's Data Protection Officer is Lee Shailer and he can also be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

***Your personal data will be processed so long as it is required for the research project.***

If we are able to anonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

## **What will happen with the results of this study?**

We aim to publish, in an academic journal, a paper containing analysis of the information collected in this study. As mentioned above, no individuals will be identified in this paper.

## **Will I see the results of the study?**

At the end of the project, after analysing all the information gathered from all participants, we will send you a newsletter summarizing the findings of the study. No individuals will be identified in these newsletters – we will just summarize what we found overall.

**Will information about my child or myself be available to anyone?**

All information collected from you during the course of this research will be kept strictly confidential and anonymous.

**Who will have access to the research records?**

Only the interviewer will have access to your videotape, which will be identified by an ID number. After analysis this videotape will be deleted (approximately 1 year after the interview).

Only the research team will have access to the text of the transcribed interview.

All of the above material will be stored on an encrypted hard disk.

**How to contact the researchers?**

If you would like to know more about this research you can contact Stefanella Costa Cordella on [REDACTED] or email her at [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk)

If you have any concerns about the research, or wish to make a complaint, you can contact the Principal Researcher using the details below:

Dr. Patrick Luyten  
Director of PhD in Psychoanalytic Studies  
Research Department of Clinical, Educational and Health Psychology  
University College London  
1-19 Torrington Place.  
London WC1E 7HB  
[p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk)

If you have any doubt or concern about your rights as a participant in this research you can contact the Medical Doctor Counsellor of the Juvenile Diabetes Foundation using the details below:

Dr. Franco Giraudó  
Fundación Diabetes Juvenil  
Lota 2344, Providencia.  
Santiago de Chile  
[REDACTED]  
[fgiraudó@diabeteschile.cl](mailto:fgiraudó@diabeteschile.cl)

**Thank you for reading this information sheet and for considering taking part in this study.**

**You will be given a copy of this information sheet before the interview.**

*(this document was showed in Spanish)*

**Participant Information Sheet For Parents/Carers**

UCL Research Ethics Committee Approval ID Number: 8899/002

**Mentalizing Diabetes in the Mother-Child Dyad**

Division of Psychology and Language Sciences, University College London.

Researcher: Stefanella Costa Cordella ([stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk))

Principal Researcher: Patrick Luyten ([p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk))

We would like to invite your child to take part in a research study that aims to understand better the relationship between mothers and children with diabetes in order to provide them with more effective treatments.

Before deciding if you would like your child to take part, it is important for you to know why the research is being carried out and what it will involve. Please take time to read this information sheet carefully and discuss it with others if you wish. If anything is unclear, or if you would like more information, do not hesitate to contact the researcher on +56998889682 or at [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk).

**The aim of the study**

We want to find out how the relationship between mothers and children affects the way they cope with the task of managing diabetes and the level of control they achieve over the illness. We also want to explore the personal experience of mothers (that is, how they feel, what they think, what it is happening in their minds) regarding their child's diabetes, as well as the experience of the child regarding his/her own diabetes.

**Why is the study being done?**

We know from previous studies that the way in which people deal with chronic illness is linked with how they relate to other people. In key respects, managing relationships is just like dealing with aspects of illness.

We also know from previous studies that the wellbeing and quality of life of caregivers of diabetic children can be affected by the burden of taking care of a child with a chronic illness.

Another thing that we have seen in previous studies is that children with diabetes are more likely to be affected psychologically by the illness and its implications. Taking this together, we think it would be helpful to understand these things better in order to develop interventions that consider both the mother and child's perspectives to help them deal with diabetes in a better way.

### **Why have we been asked to take part?**

We are contacting your child because his/her mother took part in a survey during the first part of our research and expressed an interest in being contacted for a follow-up study. We are now interested in exploring the psychological aspects of type 1 diabetes in depth, through a one-to-one interview with affected children.

### **Does my child have to take part in this study?**

It is up to you to decide if your child will take part. If you decide to go ahead you will be contacted again and asked to sign a consent form. Your child can withdraw from the study at any time without giving a reason and without for this. If this happens you can decide what will happen to the data she/he has provided up to that point.

### **What will happen if we take part?**

If you agree to your child taking part, we will ask him/her some questions, in person, about his/her experience of the relationship with his/her mother. This is a standard interview that has been used in several studies around the world.

If certain questions are difficult to answer, or your child simply does not want to answer them, he/she can tell the researcher this and the interview will move on.

**Your child does not have to answer any question that he/she does not want to.**

If at any moment you or your child want to stop participating, **you can do so without having to explain why.**

If you decide to take part in the interview, following the completion of this process a £15 voucher as a thank you for your time and effort.

The whole process should take 40-50 minutes of your child's time.

### **Will the interview be recorded and how will the recording be used?**

This interview will be videotaped for analysis purposes. The videotape will be safely stored on an encrypted hard disk, with the password known only to the researcher. The recording will be transcribed and only the members of the research team will have access to this text. Your child will be identified in the text only by an ID number - his/her name will not appear in any record. The videotape will be deleted after analysis (one year after the interview takes place).

**What are the possible disadvantages and risks of taking part?**

We hope that your child finds the interview interesting and useful. We do not envisage that the questions we ask will cause significant discomfort. However, some questions might make your child think about experiences that are difficult to deal with and/or that he/she thinks are too personal to talk about. Please remember that he/she does not have to answer any questions that he/she does not want to. Also, if you or your child want to talk to a qualified person about any of the issues raised in this interview we will be happy to help with that. You can write to [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk) if you have any question or if you want us to put you in touch with qualified professionals.

**What are the possible benefits of taking part?**

We will use the information you provide to develop a theory of how new psychological treatments for children with type 1 diabetes and their caregivers can be designed, and to help health providers improve the support they currently provide.

**What if something goes wrong?**

We hope that your child's participation in this research will be a positive experience. However, if you or your child need to complain about any aspect of his/her participation, you can contact the Principal Researcher of this study (details provided below). If you are not happy with the response you receive, you can write to the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

**Will my child's participation in this project be kept confidential\*?**

All information we collect about your child during the course of the research will be kept strictly confidential. A video and transcript of your child's interview will be saved with an ID number, so his/her name will not appear in any of our records. These files will be stored on an encrypted hard disk, with the password known only to the researcher. Your child will not be identifiable in any ensuing reports or publications.

**\*Limits to confidentiality**

- Please note that confidentiality will be maintained as far as is possible. However, the researcher has a duty to report to relevant authorities information received which suggests possible harm/danger to the participant or others.
- Please note that absolute confidentiality cannot be guaranteed due to the limited size of the participant group.

- Confidentiality will be respected subject to legal constraints and professional guidelines.
- Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. We would inform you of any circumstances that might limit your confidentiality.

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Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

***Your personal data will be processed so long as it is required for the research project.***

If we are able to anonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

## **What will happen with the results of this study?**

We aim to publish, in an academic journal, a paper containing analysis of the information collected in this study. As mentioned above, no individuals will be identified in this paper.

## **Will I see the results of the study?**

At the end of the project, after analysing all the information gathered from all participants, we will send you a newsletter summarizing the findings of the study. No individuals will be identified in these newsletters – we will just summarize what we found overall.

## **Will information about my child or myself be available to anyone?**

All information collected from you and your child during the course of this research will be kept strictly confidential and anonymous.

### **Who will have access to the research records?**

Only the interviewer will have access to the videotapes of interviews, which will be identified by an ID number. After analysis these videotapes will be deleted (approximately 1 year after the interview).

Only the research team will have access to the text of the transcribed interview.

All of the above material will be stored on an encrypted hard disk.

### **How to contact the researchers?**

If you would like to know more about this research you can contact Stefanella Costa Cordella on +56998889682 or email her at [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk)  
If you have any concerns about the research, or wish to make a complaint, you can contact the Principal Researcher using the details below:

Dr. Patrick Luyten  
Director of PhD in Psychoanalytic Studies  
Research Department of Clinical, Educational and Health Psychology  
University College London  
1-19 Torrington Place.  
London WC1E 7HB  
[p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk)

If you have any doubt or concern about your rights as a participant in this research you can contact the Medical Doctor Counsellor of the Juvenile Diabetes Foundation using the details below:

Dr. Franco Giraudo  
Fundación Diabetes Juvenil  
Lota 2344, Providencia.  
Santiago de Chile  
0223673900  
[fgiraudo@diabeteschile.cl](mailto:fgiraudo@diabeteschile.cl)

**Thank you for reading this information sheet and for considering your child's participation in this study.**

**You will be given a copy of this information sheet before your child's interview.**

*(this document was showed in Spanish)*



## Diabetes and the mother-child relationship

### Consent form for children:

Thank you very much for your help!!!

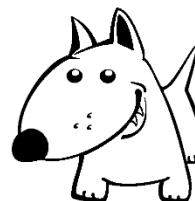
Now that you have read our information sheet, we would like to ask you some things, just to be sure that you are happy to take part in our project. If you have any questions right now, please ask Stefanella, the interviewer. If you think of a question later, you can e-mail her at [stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk). If you agree with the sentences below, please tick the boxes next to them. We will give you and your mum a copy of this page and a copy of the information sheet.

### **If yes, please tick the following:**

- ☐ I have read the Information Sheet and understand what the study is about.
- ☐ I have had the opportunity to ask any questions I wish to ask.
- ☐ I understand that my name and the videotape of my interview will be kept a secret and that only the people who are doing the research will see the videotape.
- ☐ I understand that I am free to stop taking part in this study at any time without any problem.
- ☐ I understand that I do not have to take part in this study if I do not want to.
- ☐ I have the names and telephone numbers of the people doing the research in case I want to ask them something.
- ☐ I agree that the research project named above has been explained to me and I agree to take part in this study.

Thank you very much for your help!!!

*(this document was showed in Spanish)*







## Consent form for mothers

### Diabetes and the mother-child relationship

Division of Psychology and Language Sciences, University College London.

Patrick Luyten ([p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk))

Stefanella Costa Cordella ([stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk))

UCL Data Protection Officer: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

*This study has been approved by the UCL Research Ethics Committee: Project ID number: 8899/002*

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether or not to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent to any one element I may not be eligible to take part in the study.**

**TICK  
BOX**

**I confirm that I have read and understood the information sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and I would like to take part in an individual interview**

**I understand that I will be able to withdraw my data**

**I consent to the processing of my personal information – in the form of a videotape of my interview – for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.**

**I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.**

**I understand that the data gathered in this study will be stored anonymously and securely. it will not be possible to identify me in any publications.**

**I understand that my information may be subject to review by responsible individuals from the university for monitoring and audit purposes.**

**I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.**

**I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted, unless I agree otherwise.**

**I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.**

**I understand the direct/indirect benefits of participating.**

**I understand that the data will not be made available to any commercial organisations and is the sole responsibility of the researcher(s) undertaking this study.**

**I understand that I will not benefit financially from this study any outcome of it.**

**I understand that I will be compensated for the time spent in the study (if applicable) and fully compensated if I choose to withdraw.**

**I agree that my anonymized research data may be used by others for future research. [no one will be able to identify you when this data is shared.]**

**I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. yes/no**

**I consent to my interview being audio/video recorded and understand that the recordings will be destroyed immediately following transcription.**

**i hereby confirm that I understand the inclusion criteria as detailed in the information sheet and explained to me by the researcher.**

**i hereby confirm that:**

**(A) I understand the exclusion criteria as detailed in the information sheet and explained to me by the researcher; and**

**(B) I do not fall under the exclusion criteria.**

**I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.**

**I am aware of who I should contact if I wish to lodge a complaint.**

**I voluntarily agree to take part in this study.**

**use of information for this project and beyond**

**I am happy for the data I provide to be stored on an encrypted hard drive disk for a period of up to one year.**

**I understand that other authenticated researchers will have access to my anonymized data.**

*(this document was presented in Spanish)*



## Consent form for Parents/Carers

### Diabetes and the mother-child relationship

Division of Psychology and Language Sciences, University College London.

Patrick Luyten ([p.luyten@ucl.ac.uk](mailto:p.luyten@ucl.ac.uk))

Stefanella Costa Cordella ([stefanella.cordella.15@ucl.ac.uk](mailto:stefanella.cordella.15@ucl.ac.uk))

UCL Data Protection Officer: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

*This study has been approved by the UCL Research Ethics Committee: Project ID number: 8899/002*

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether or not to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent to any one element I may not be eligible to take part in the study.**

	TICK BOX
I confirm that I have read and understood the information sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and I would like to take part in an individual interview	
I understand that I will be able to withdraw my data	
I consent to the processing of my personal information – in the form of a videotape of my interview – for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.	
I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.	
I understand that the data gathered in this study will be stored anonymously and securely. it will not be possible to identify me in any publications.	
I understand that my information may be subject to review by responsible individuals from the university for monitoring and audit purposes.	

**I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.**

**I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted, unless I agree otherwise.**

**I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.**

**I understand the direct/indirect benefits of participating.**

**I understand that the data will not be made available to any commercial organisations and is the sole responsibility of the researcher(s) undertaking this study.**

**I understand that I will not benefit financially from this study any outcome of it.**

**I understand that I will be compensated for the time spent in the study (if applicable) and fully compensated if I choose to withdraw.**

**I agree that my anonymized research data may be used by others for future research. [no one will be able to identify you when this data is shared.]**

**I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. yes/no**

**I consent to my interview being audio/video recorded and understand that the recordings will be destroyed immediately following transcription.**

**i hereby confirm that I understand the inclusion criteria as detailed in the information sheet and explained to me by the researcher.**

**i hereby confirm that:**

**(C) I understand the exclusion criteria as detailed in the information sheet and explained to me by the researcher; and**

**(D) I do not fall under the exclusion criteria.**

**I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.**

**I am aware of who I should contact if I wish to lodge a complaint.**

**I voluntarily agree to take part in this study.**

**use of information for this project and beyond**

**I am happy for the data I provide to be stored on an encrypted hard drive disk for a period of up to one year.**

**I understand that other authenticated researchers will have access to my anonymized data.**

*(this document was presented in Spanish)*

**APPENDIX F**  
**NOTIFICATION OF ETHICAL APPROVAL STUDY 3**



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31<sup>st</sup> January 2018

Dr Patrick Luyten  
Department of Psychoanalysis  
Research Department of Clinical, Educational and Health Psychology  
UCL

Dear Dr Luyten

**Notification of Ethics Approval with Provisos**

**Project ID/Title: 8899/002: Mentalizing diabetes in the mother-child dyad**

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that the data collection element of your study has been ethically approved by the UCL REC until 31<sup>st</sup> January 2019.

Ethical approval is subject to the following conditions:

**Notification of Amendments to the Research**

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

**Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Final Report**

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

## **APPENDIX G**

### **CAI TRAINING CERTIFICATE**

## **Child Attachment Interview training**

To Whom It May Concern:

This is to certify that

**Stefanella Costa Cordella**

Attended the **Child Attachment Interview** training on 28<sup>th</sup> February – 3<sup>rd</sup> March 2017 at the Anna Freud National Centre for children and Families.

Signed:



.....

Yael Shmueli-Goetz  
Course Leader

Our Patron: **Her Royal Highness The Duchess of Cambridge**

Anna Freud National Centre for Children and Families is a company limited by guarantee, company number 03819888, and a registered charity, number 1077106.



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